

# **COVID-19** at the Intersection of Gender and Disability:

Findings of a Global Human Rights Survey, March to April 2020

Women Enabled International



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Cover image depicts three house shapes in shades of gray, each with a window. In each window is a person. One has curly hair and is in a wheelchair, one has long hair and is signing in sign language, and one wears a headscarf and is looking downward. Above and behind the houses is a large red virus cell shape.

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The survey on which this report is based was drafted by Amanda McRae and was translated into Spanish and English Plain Language by Ana Maria Sanchez Rodriguez (WEI Volunteer), Suzannah Phillips, Anastasia Holoboff (WEI Senior Legal Advisor), and Linda Carlton. Amanda McRae, Ana Maria Sanchez Rodriguez, Rigat Keleta (WEI Program Fellow) and Radhika Saxena (WEI Legal Fellow) analyzed the survey results. All of the above-named individuals as well as Brittany Evans (WEI Program Assistant) and Madelyn Jones (WEI Social Media Intern) assisted with distribution of the survey. WEI is particularly thankful to Ana Maria Sanchez Rodriguez and Linda Carlton, who volunteered their time to assist with this project.

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A special thank you to all of the individuals who completed the WEI survey for sharing their experiences with the COVID-19 crisis. We hope we have done justice to your experiences in this report and that this report leads to a tangible positive impact on your lives.

#### **Introductions and Key Recommendations**

In March 2020, Women Enabled International (WEI) identified a gap in initial global responses to COVID-19: many actors were discussing how to include women and persons with disabilities in the response, but few were considering the unique experiences of women with disabilities and others living at the intersection of gender and disability. At the same time, we were hearing from local advocates that they were distressed about the situations in their countries and had concerns about the impact of this crisis on women with disabilities in particular, especially with respect to violence, access to health goods and services, and meeting basic needs. As such, WEI created the WEI COVID-19 Survey (Survey) to better understand these issues and how the lives of women, girls, non-binary, trans, and gender non-conforming persons with disabilities were being impacted by the COVID-19 crisis.

One hundred women, non-binary, and trans persons with disabilities across the globe responded to this Survey, which asked respondents to identify concerns they had about healthcare, violence, support services, income, and education. Survey respondents identified that their mental and physical health was being negatively impacted by this crisis, that they feared healthcare shortages combined with discrimination would mean they would not receive needed care if they were to become sick, that they were having trouble meeting their basic needs, and that many were in fear for their personal safety. For instance, Survey respondents reported that:

"I have had days of extreme crisis and no support. Mental health is not like physical health. You cannot put it on hold. You have to manage it daily and if you don't it will get worse and be difficult to recover."1

"I heard about that [healthcare rationing] on Facebook. That makes me really scared to go to the hospital. Petrified."2

"I fear I may run out of food. I was not prepared for this. The government is distributing food only in the city centre."3

"Before, I had a person who helped me change and bathe every day. With this situation the service is not available and I feel powerless to handle my own hygiene."4

"My family is emotionally abusive, and I am trapped in a house with them." 5

These are all issues that many women, girls, non-binary, trans, and gender non-conforming persons with disabilities experience in their everyday lives, often due to stigma, stereotypes, and discrimination at the intersection of gender and disability. The COVID-19 pandemic has amplified these abuses, and we hope this report will bring these issues out of the shadows.

This report first provides a summary of the Survey, including its methodology, the characteristics of respondents. and its limitations. The report then summarizes findings from the Survey related to health, meeting basic needs, and violence, presenting the voices of the respondents in their own words as frequently as possible, backed up by limited secondary research and a summary of human rights obligations related to these issues. The report concludes with recommendations to States, U.N. agencies, healthcare systems, and violence service providers about how to ensure that issues at the intersection of gender and disability are included in COVID-19 responses moving forward.

A woman with psychosocial disabilities, age 48. Note that all Survey respondents were asked to provide consent to the use of any identifying information alongside quotations or other information shared in the survey. Any identifying information included in this report—first name, age, location, type of disability, gender or gender-identity—is used with the express permission of Survey respondents and varies across respondents.

Linda, a woman with an intellectual disability, age 41, New York, U.S.

A woman from Uganda.

Rosario, a woman with muscular dystrophy, age 23, Argentina, translated from Spanish ("Antes tenía una persona que me asistía a cambiarme y bañarme todos los días. Con ésta situación se hace imposible el servicio y me siento impotente frente a mi propia hygiene.").

Alex, a non-binary autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S.

#### **Key Recommendations to States**

- Involve women, girls, non-binary, trans, and gender non-conforming persons with disabilities in planning for and implementation of the COVID-19 government and healthcare responses.
- ▶ Issue specific guidance to healthcare providers on ensuring rights-based care during the COVID-19 crisis that makes clear that discrimination on prohibited grounds, including at the intersection of gender and disability, is not permitted.
- Classify disability-related support services and gender-based violence services as essential services during COVID-19 lockdowns, stay-in-place orders, or other restrictions on movement and ensure a streamlined process for obtaining any needed permits for movement for these service providers.
- Urgently adopt social protection measures—including income supplementation, rent subsidies and eviction moratoriums, food subsidies, and free clean water and hygiene measures, including menstrual hygiene—to fill the gap in income for all persons so that they can meet their basic needs. Ensure those who worked as freelancers, entrepreneurs, or in the informal sector or who receive other types of income support are eligible for these measures.
- Undertake particular efforts to reach women, girls, non-binary, trans, and gender non-conforming persons with disabilities with social protection measures, including through campaigns that provide information in a variety of accessible formats, and ensure that social protection goes directly to these individuals rather than to families or partners.

#### The Survey: Methodology, Characteristics of Respondents, and Limitations

This report is based on the results of a global survey conducted in March and April 2020, targeted at the personal experiences of women, girls, non-binary, trans, and gender non-conforming persons with disabilities. This survey, which was intended to be primarily qualitative, asked respondents to provide narrative information about the following topics: access to health services, including sexual and reproductive health services; rationing of healthcare; personal safety and violence; access to support services to meet daily living needs; and access to education, employment, and other income.

The survey was conducted virtually via a Word document and Google Form in English, Spanish, and English plain language. It was made public and distributed via social media channels, listservs, and through other organizations working on women's rights and/or disability rights. The survey received 100 responses from women, non-binary, and trans persons with disabilities. This included 32 responses in Spanish, 2 responses in Portuguese, and 66 responses in English.

Survey respondents were asked for their consent to use information from their survey responses in this report and WEI's other work and were further asked for consent for WEI to include any identifying information, including first name, age, location, gender and gender identity, and disability alongside the information they provided. WEI obtained consent to use all responses and identifying information included in this report. Survey results have been lightly edited only to resolve typographical errors.

The survey and its results have several limitations. Due to the nature of this survey, it could not reach those without internet access or those who do not speak or read English or Spanish. The survey disproportionately reached individuals in North America (particularly the United States of America (U.S.) and Mexico) and does not proportionately represent other regions (particularly Asia-Pacific). This survey also could not reach persons with disabilities whose liberty is restricted, including those who are in social care institutions, psychiatric hospitals, or prisons or jails. It further did not reach many persons with intellectual disabilities, did not reach any girls with disabilities (under 18 years of age), and did not reach anyone who identified as a refugee or displaced person or who was living in a conflict zone. We recognize that these are groups whose rights may be particularly impacted by COVID-19 and the government and healthcare responses to this pandemic, and we hope that further stages of research can reach these groups. In this report, we raise some issues that likely are impacting these groups, based on secondary information.

#### **CHARACTERISTICS OF SURVEY RESPONDENTS**

#### Age Group

| Under 18          | 0 |
|-------------------|---|
| 18 to 29 <b>2</b> | 4 |
| 30 to 45 <b>4</b> | 1 |
| 46 to 60 <b>2</b> | 2 |
| 60 to 75 <b>1</b> | 3 |
| Over 75           | 0 |

#### **Geographic Location**

| Asia-Pacific                 | 10 |
|------------------------------|----|
| Central and South America    | 17 |
| Europe                       | 11 |
| Middle East and North Africa | 2  |
| Sub-Saharan Africa           | 13 |
| North America                | 41 |
| Australia and New Zealand    | 3  |
| Not specified                | 3  |
|                              |    |

#### **Gender or Gender Identity**

| Woman      | 91 |
|------------|----|
| Non-binary | 7  |
| Trans      | 1  |
| Other      | 1  |

#### **Disability**

| Physical impairment            | 58         |
|--------------------------------|------------|
| Psychosocial disability        | <b>1</b> 5 |
| Hearing impairment/Deaf        | 8          |
| Visual impairment/Blind        | 7          |
| Autistic                       | 4          |
| Albinism                       | 2          |
| Intellectual Disability        | 1          |
| Deafblind                      | 1          |
| Other or Multiple Disabilities | 2          |
| Not identified                 | 2          |
|                                |            |

#### "Now more than ever it is clear to us that we have no social value...."6

COVID-19 and the government and healthcare responses have exacerbated the gap in rights for marginalized communities, including those living at the intersection of gender and disability. This section will summarize findings from the Survey related to three important topics—health, meeting basic needs, and violence—while drawing on human rights standards and limited secondary research to highlight the importance of these topics for women. girls, non-binary, trans, and gender non-conforming persons with disabilities. As much as possible, this section will use the words of the Survey respondents themselves to illustrate the impact of COVID-19 on their lives and experiences.

#### **Ensuring the Right to Health**

Women, girls, non-binary, trans, and gender non-conforming persons with disabilities are experiencing decreased access to health goods and services and negative impacts on their physical and mental health due to COVID-19.

Everyone has the right to the highest attainable standard of physical and mental health. Although the right to health is considered a right of progressive realization, in that implementation of that right is dependent on a State's finances and level of development, the U.N. Committee on Economic, Social, and Cultural Rights (ESCR Committee) has found that every State has a core obligation to ensure "minimum essential levels" under this right, including to ensure "the right of access to health facilities, goods and services on a nondiscriminatory basis, especially for vulnerable or marginalized groups."8 Indeed, the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) specifically require that States ensure the right to health for persons with disabilities and for women on an equal basis with others and without discrimination.9 The ESCR Committee has further found that, in times of emergency, "[p]riority in the provision of international medical aid, distribution and management of resources, such as safe and potable water, food and medical supplies, and financial aid should be given to the most vulnerable or marginalized groups of the population,"10 which includes many women, girls, non-binary, trans, and gender non-conforming persons with disabilities.

Within these core obligations under the right to health, States must ensure:

Access to health services that people need specifically because of their gender and/or disability, including sexual and reproductive health services (such as abortion, contraception, maternal health services, reproductive cancer screenings, etc.) and disability-related services (including pain management, physical therapy, rehabilitation, etc.);11

Yolanda, a woman with a physical disability, age 55, Canada, translated from Spanish ("Ahora más que siempre nos queda claro que no tenemos ningún valor social dentro del esquema neoliberal.").

Universal Declaration of Human Rights, adopted Dec. 10, 1948, art. 25, G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948) [hereinafter UDHR]: International Covenant on Economic, Social and Cultural Rights, adopted Dec. 16, 1966, art. 12, G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966) (entered into force Jan. 3, 1976) [hereinafter ICESCR].

<sup>8</sup> ESCR Committee, General Comment No. 14, The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), para. 43(a), U.N. Doc. E/C.12/2000/4 (2000). [hereinafter ESCR Committee, Gen. Comment No. 14].

See Convention on the Elimination of All Forms of Discrimination against Women, adopted Dec. 18, 1979, art. 12, G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46, U.N.T.S. 13 (entered into force Sept. 3, 1981) [hereinafter CEDAW]; Convention on the Rights of Persons with Disabilities, adopted Dec. 13, 2006, art. 25, G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611, (entered into force May, 3 2008) [hereinafter CRPD].

<sup>10</sup> ESCR Committee, Gen. Comment No. 14, supra note 8, para. 40.

<sup>11</sup> Id., para. 44; CEDAW, supra note 9, art. 12; CRPD, supra note 9, art. 25; CEDAW Committee, General Recommendation No. 24: Women and health, para. 11, U.N. Doc, CEDAW/C/GC/24 (1999).

Respect, protection, and fulfillment of the right to health for all, including by ensuring availability of accessible, acceptable, and quality health information, goods, and services. 12 This requires that States ensure that access to healthcare facilities, goods, and services is provided on a non-discriminatory basis, including discrimination based on gender or disability; that available health facilities, goods, and services are distributed equitably; and that States ensure that healthcare facilities and providers are given training on human rights.13

COVID-19 is a healthcare crisis that has been testing States' implementation of the right to health, particularly for the most marginalized. During the COVID-19 crisis, healthcare has changed in several respects. Many health services have either been cancelled, thereby delaying needed care, or moved to virtual means like telehealth, which are not always accessible or adequate to meet the sometimes-complex needs of people living at the intersection of gender and disability.

Specifically. States have taken measures that impact access to sexual and reproductive healthcare and that can have a disproportionate impact on women, girls, non-binary, trans, and gender non-conforming persons with disabilities. For instance, some States have attempted to limit access to certain sexual and reproductive health services, particularly abortion, during the COVID-19 crisis by classifying abortion as a non-essential service (U.S. states of Texas and Ohio)<sup>14</sup> or attempting to adopt laws that further restrict access to abortion (Poland).<sup>15</sup> In Italy, some hospitals that had previously provided abortions stopped providing the service and sent women elsewhere for care, making obtaining an abortion much more complicated.16 Women with disabilities may be particularly affected by such restrictions and complications, because, due to societal discrimination, they are more likely to have lower levels of education and less access to employment resulting in lower incomes, and so frequently cannot afford to travel far from their homes for abortion, while women with mobility-related disabilities face additional barriers to travel, as the means of travel are often inaccessible. <sup>17</sup> Furthermore, in order to prevent the spread of COVID-19, some hospitals adopted or considered adopting policies that disallowed any support persons, including partners, from accompanying a pregnant person during labor, delivery, and the postpartum period.<sup>18</sup> These policies did not carve out exceptions for pregnant persons with disabilities and would have had a disproportionate impact on them, as they may need support persons simply to communicate with healthcare personnel or to get assistance meeting personal hygiene needs while hospital staff are overstretched.

Additionally and distressingly, as healthcare shortages increase, States and healthcare providers may be placed in a position to make decisions about who does and does not receive care, a process known as "rationing." This rationing may, due to entrenched discrimination, leave behind the most marginalized, including many women, girls, non-binary, trans, and gender non-conforming persons with disabilities.<sup>20</sup>

This section explores, based on Survey responses, how (1) increased barriers to physical, mental, and sexual and reproductive health goods and services and (2) concerns about rationing of healthcare are impacting the physical and mental health of women, girls, non-binary, trans, and gender non-conforming persons with disabilities worldwide.

- 12 ESCR Committee, Gen. Comment No. 14, supra note 8, para. 12.
- 13 Id., paras. 12, 43-44.
- 14 Sabrina Tavernise, "Texas and Ohio Include Abortion as Medical Procedure that Must Be Delayed, N.Y. Times, Mar. 21, 2020, https://www. nytimes.com/2020/03/23/us/coronavirus-texas-ohio-abortion.html.
- 15 Shaun Walker, "Concerns over Polish government tightening abortion laws during Covid-19 crisis," The Guardian, Apr. 14, 2020, https://www. theguardian.com/world/2020/apr/14/concerns-over-polish-government-tightening-abortion-laws-during-covid-19-crisis.
- 16 Laura Smith-Spark, "Abortion access thrown into jeopardy by coronavirus pandemic," CNN, Apr. 9, 2020, https://www.cnn.com/2020/03/27/health/coronavirus-abortion-access-intl/index.html.
- 17 Inclusion Ireland, "Inclusion Ireland Joins 'Together for Yes'" 5 (May 2018), http://www.inclusionireland.ie/sites/default/ files/attach/newsitem/1680/inclusion-ireland-together-yes.pdf.
- 18 Christina Caron & Katie Van Syckle, "Some Pregnant Women in New York City Will Have to Deliver Babies Alone," N.Y. Times, Mar. 24, 2020, https://www.nytimes.com/2020/03/24/parenting/coronavirus-labor-birth.html?fbclid=lwAR030piD\_a1LrkjAolxM3cKM31TEfUHKShu1mNmd65L pi0a0w0Jrdvuo7X8.
- 19 See, e.g., Jason Horowitz, "Italy's Health Care System Groans Under Coronavirus a Warning to the World," N.Y. Times, Mar. 12, 2020, https:// www.nytimes.com/2020/03/12/world/europe/12italy-coronavirus-health-care.html.
- 20 See, e.g., Joseph Shapiro, "People with Disabilities Say Rationing Care Policies Violate Civil Rights," NPR.org, Mar. 23, 2020, https://www. npr.org/2020/03/23/820398531/people-with-disabilities-say-rationing-care-policies-violate-civil-rights/; Katelyn Burns, "Coronavirus isn't transphobic. But America's economic and health systems are," Vox.com, Apr. 3, 2020, https://www.vox.com/identities/2020/4/3/21204305/ coronavirus-transgender-economy-health-care.

#### Access to Physical, Mental, and Sexual and Reproductive Health Goods and Services

The majority of Survey respondents (61) reported that COVID-19 had affected their access to their usual health services, medications, and equipment. Many reported that their usual medical appointments and needed procedures, including those related to their gender or disability, were being cancelled or pushed back,21 with resources in some cases being diverted to the COVID-19 pandemic instead.<sup>22</sup>

- Alex, a non-binary person with multiple disabilities in the U.S. state of Texas, noted that: "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..."23
- Sheila May, a woman with low vision in the Philippines, reported that government orders were discouraging non-emergency cases from coming to the hospital for other kinds of treatment.<sup>24</sup>
- Gina Rose, a woman with a visual impairment also from the Philippines, expressed fear of acquiring COVID-19 if she left the house to access health services.<sup>25</sup>

Women with disabilities also reported that their pain management and physical therapy appointments had been cancelled or delayed, leading to pain for some and likely also decrease in bodily function.<sup>26</sup> As a 48-year-old woman from the Netherlands described, "I can't go to physical therapy and that's why I'm hurrying [hurting] much more." 27

Survey respondents also identified increased barriers to accessing healthcare goods and services they needed specifically because of their gender or gender identity, including sexual and reproductive health services. They reported significant barriers to accessing, for instance, regular sexual and reproductive health check-ups,<sup>28</sup> breast cancer screenings.<sup>29</sup> pregnancy-related services.<sup>30</sup> menopause services.<sup>31</sup> and abortion.<sup>32</sup> Two non-binary individuals identified that their access to hormones has become more difficult. 33 These barriers sometimes caused Survey respondents mental distress or threatened their overall health.

- One Survey respondent with chronic illness who was nine weeks pregnant was experiencing nausea and migraines and reported being worried about her health. "I cannot visit my acupuncturist for the nausea. My pregnancy related care is usually on the telephone instead of in person, except for the ultrasounds."34
- A 48-year-old woman with psychosocial disabilities reported that "[1] am putting off treatment for menopause due to the crisis, which is not good because my mental health condition is compounded by the stress of the crisis and menopause (which is so rarely listed as a women's health issue)."35

<sup>21</sup> A non-binary person with depression, age 25, California, U.S.; A woman with psychosocial disabilities, age 48; Rachael, a woman with mobility and movement-related disabilities, age 42, U.S.; Alex, a non-binary autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S.; Angélica, a woman with a physical disability,, age 53, El Salvador; Laura, a woman with a psychosocial disability, age 38, Mexico.

<sup>22</sup> A woman with psychosocial disabilities, age 48.

<sup>23</sup> Alex, a non-binary autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S.

<sup>24</sup> Sheila May, a woman with low vision, age 29, the Philippines.

<sup>25</sup> Gina Rose, a woman with a visual impairment, age 37, the Philippines.

<sup>26</sup> A woman, age 48, the Netherlands; Survey from a person who does not wish to be identified; Rachael, a woman with mobility and movementrelated disabilities, age 42, U.S.

<sup>27</sup> A woman, age 48, the Netherlands

<sup>28</sup> Cassandra, a woman with diabetes and a compromised immune system, age 25, U.S.; Celeste, a woman with a visual impairment, age 19,

<sup>29</sup> Yolanda, a woman with a physical disability, age 55, Canada.

<sup>30</sup> A woman with chronic illness, age 34.

<sup>31</sup> A woman with psychosocial disabilities, age 48.

<sup>32</sup> Marcela, a woman with a psychosocial disability, age 59, Chile.

<sup>33</sup> Alex, a non-binary autistic person with physical, emotional, and mental disabilities age 23, Texas, U.S.; Gwen, a non-binary autistic person, age 24, France.

<sup>34</sup> A woman with chronic illness, age 34.

<sup>35</sup> A woman with psychosocial disabilities, age 48.

Marcela, a woman with a psychosocial disability in Chile, noted that the law in that country already limits access to abortion, particularly for women and girls with disabilities who have been placed under guardianship and for those who face conscientious objection from providers, and that COVID-19 would compound those barriers.36

Survey respondents also reported that lockdowns, shelter-in-place orders, and other rules around movement, as well as wearing masks and social distancing, are making access to health services more difficult.

- ▶ For instance, Andrea, a woman with a visual impairment in Argentina, expressed that she would have difficulties accessing health services because "there is a total ban on the movement of people, except for essential cases, and because of my disability, I depend on the help of third parties to cross the streets."37
- ▶ A Deaf woman from Brazil also noted that, "In general, for me, the barriers are of a communication nature, in this case, the health providers must write things down for me because the use of masks prevents my lipreading."38

For many Survey respondents, telehealth services were not an adequate substitute, because they did not have the needed technology, the technology was not fully accessible, they doubted the quality of care, or they were afraid their insurance would not cover it.39

- As one respondent noted, "Mental health services moved to telehealth, but clarity around coverage has been unclear - so I don't know if I can get government rebates like I would normally under my mental health care plan."40
- As a woman from Brazil reported, "As a disabled person I feel more anxious about the lack of access to health services and the difficulties I may face to communicate by phone, due to my hearing impairment."41

Restrictions on public and private transportation as a result of COVID-19, or discomfort with using these services, have also posed significant barriers to many Survey respondents accessing needed health services. 42

- Lyness, a woman with a physical disability in Malawi, reported that "Transport has doubled [in price] of which I cannot afford and I cannot walk to the hospital"43
- Namugabwe, a woman with a psychosocial disability, reported that, in her context, "Public transport means was barned [banned], so accessing a health facility is not easy."44
- Gina Rose, a woman with a physical disability from the Philippines, also reported the barriers posed by lack of access to transport: "Supposedly I have my follow up check-up but since we are on quarantine, I prefer not to go to the hospital because there is no public vehicle."45

<sup>36</sup> Marcela, a woman with a psychosocial disability, age 59, Chile, translated from Spanish ("La cuarentena obligatoria comunal deja libre acceso a servicios esenciales del comercio como servicios de salud publico o comercial, el aborto esta regido por la Ley de 3 causales, y ya era difícil que los servicios públicos aplicaran este derecho a las mujeres que reúnen los requisitos por tema de objeción de conciencia y por Interdiccion en caso de mujeres y niñas con discapacidad").

<sup>37</sup> Andrea, a woman with a visual disability, age 33, Argentina, translated from Spanish ("Por el momento no afectó esos servicios porque no los necesité. Pero en caso de necesitarlos, supongo que se verían afectados, ya que por el momento hay prohibición total de circulación de personas, salvo para casos esenciales, y por mi discapacidad, dependo de la ayuda de terceros/as para cruzar las calles.").

<sup>38</sup> A Deaf woman, age 44, Brazil.

<sup>39</sup> A woman with physical disability and chronic health condition, age 26, New York, U.S.: Brenda, a woman with post-traumatic stress disorder, age 43, U.S.; Karina, a woman with mental disabilities, age 41, U.S.; Cassandra, a woman with diabetes and a compromised immune system, age 25,

<sup>40</sup> Survey from a person who does not wish to be identified.

<sup>41</sup> Marilene, a woman with a hearing impairment, age 46, Brazil.

<sup>42</sup> Lyness, a woman with physical disabilities, age 54, Malawi; Rachel, a woman with a physical disability, age 61, Malawi; Namugabwe, a person with a psychosocial disability; Gina Rose, a woman with a visual impairment, age 37, the Philippines.

<sup>43</sup> Lyness, a woman with physical disabilities, age 54, Malawi.

<sup>44</sup> Namugabwe, a person with a psychosocial disability.

<sup>45</sup> Gina Rose, a woman with a visual impairment, age 37, the Philippines.

#### **Concerns about Rationing of Healthcare**

The vast majority of Survey respondents (81) identified that healthcare rationing was occurring in their countries. in both formal and informal ways, or that they were afraid that such rationing would occur. Several respondents expressed concern about the inadequate preparedness of the healthcare system in their countries, which could lead to rationing in practice as healthcare providers have to make decisions about to whom to provide care. One respondent remarked that the lack of adequate facilities in public hospitals and the cost of care in private hospitals would in effect ration care, 46 while another respondent identified that the lack of personal protective equipment (PPE) and lack of training for healthcare personnel may also lead to rationing.<sup>47</sup> These concerns were not confined to a particular region but rather spanned the globe, from Brazil to England to Lesotho.

Some respondents identified that their healthcare systems were overloaded in normal times, let alone in a pandemic.48

- ▶ As a woman with albinism in Lesotho identified, "Lesotho has not yet expressed itself in this regard [related to rationing] as it currently has no confirmed COVID-19 case. However, it is apparent that it will do so owing to the fact that it already does not have enough healthcare equipment and facilities even to serve people under normal circumstances."49
- A woman with a hearing impairment in Brazil expressed concern not only about the healthcare system. but also about her government's preparedness: "In my country, there is a concern that the health system is unable to meet demand. Many states and cities do not have enough beds, masks and ventilators. The President of Brazil is going against the guidelines of the World Health Organization and the Ministry of Health in Brazil."50

Some Survey respondents identified shortages that were already occurring in their healthcare systems in the early days of the pandemic.

- Daisy, a non-binary person in the U.K., identified that cutbacks in expenditures in recent years may have led to the shortfall: "Our country doesn't have enough equipment due to cuts over the last 10 years by the government, so our national health service is really struggling. I'm very worried that people will get to the hospital and not be able to access ventilators."51
- ▶ A woman with a physical disability from the U.S. expressed, "There are shortages of medical supplies like alcohol swabs, rubbing alcohol, specific medications, etc. that greatly impact many people in the disabled community, myself included."52

Some respondents identified particular fears of not being able to access their usual medications, other usual health services, or COVID-19 treatments due to their disability or due to shortages in the healthcare system.

- ▶ Tamara, a woman with a skeletal muscle disorder in Mexico, shared that she would not be able to get her medications due to rationing.53
- ▶ A respondent from Uganda noted in particular: "I depend on medication for several conditions including neuritis and sinusitis, but I cannot access drugs."54

<sup>46</sup> Survey from a person who does not wish to be identified

<sup>47</sup> Janeth, a woman with a permanent medullary lesion, age 45, El Salvador.

<sup>48</sup> Rachel, a woman with a physical disability, age 61, Malawi; a woman with albinism, age 32, Lesotho; A woman with hearing disabilities, age 44, Brazil; Daisy, a non-binary person with ME, age 27, U.K.; Elizabeth, a woman with a psychosocial disability, age 45; Mexico.

<sup>49</sup> A woman with albinism, age 32, Lesotho.

<sup>50</sup> A Deaf woman, age 44, Brazil

<sup>51</sup> Daisy, a non-binary person with ME, age 27, U.K.

<sup>52</sup> A woman with physical disabilities, age 26, U.S.

<sup>53</sup> Tamara, a woman with skeletal muscle disorder, age 52, Mexico.

<sup>54</sup> A woman in Uganda.

A 48-year-old woman with psychosocial disability shared that "the fact that mental health services are not prioritised for those with mental health conditions is the key problem I am facing. It's great to offer mental health supports to others - people who are isolated, health workers, etc. - but you have to manage those with mental health problems first."55

Some respondents expressed fear about the shortage of ventilators in particular,56 including that persons with disabilities might be deprioritized concerning the use of ventilators.<sup>57</sup>

- Lisa, an autistic woman in the U.K., noted: "They are rationing ventilators and it makes me afraid that people like me won't be rescued."58
- ▶ Another respondent reported: "There is also apparently some discussion of possibly taking away ventilators belonging to disabled patients to give them to (nondisabled) covid19 patients instead, and naturally this has scared people who have been using a ventilator for years." 59

Respondents expressed fear about going to the hospital in this context, being aware of likely healthcare system overload and the potential of rationing. A few respondents described that they feared their age, disability, or other status may make them less of a priority in receiving healthcare. 60

- ▶ Gina Rose, a woman with a visual impairment from the Philippines, put it simply: "[I]f I get sick and if ever the available hospital has insufficient facilities. I have a lesser chance of recovering from the virus."61
- ▶ Gwen, from France, also noted: "I'm scared and angry that people will be discarded as not a priority because of their disabilities."62
- A non-binary person with chronic illness in the Netherlands noted "I might personally survive given that people call me high functioning, but I'm worried a lot about other disabled people."63
- ▶ The impact of potential rationing was particularly apparent from respondents based in the U.S.:
  - Linda, a woman with an intellectual disability from New York, expressed fear about what would happen to her and other residents of a group home: "I heard about that [rationing] on Facebook. That makes me really scared to go to the hospital. Petrified. ... One person was taken to the emergency room because he had a seizure. Yes, I was scared when they took him to the hospital and he had a bad cough. But they sent him home in one day."64
  - Alex, a non-binary person from Texas, described: "The information on this topic is spotty in the US, but the idea of medical professionals making those choices is deeply concerning to me. ... As someone disabled, it is a frightening thing to watch happen."65
  - A woman with a physical disability in New York noted: "I am still slightly concerned about my own 'score' on suggested 'scoring' systems."66
  - Karina, a woman with mental disabilities from Indiana, described: "They said the older people would be put last or the ones with health problems."67

<sup>55</sup> A woman with psychosocial disabilities, age 48.

<sup>56</sup> Daisy, a non-binary person with ME, age 27, U.K.

<sup>57</sup> Rosario, a woman with muscular dystrophy, age 23, Argentina.

<sup>58</sup> Lisa, an autistic woman, age 30, U.K.

<sup>59</sup> Andrea, age 50.

<sup>60</sup> Pahola, woman with tetraplegia, age 29, Guatemala; Lili, a woman with a physical disability, age 62, Mexico; Rosario, a woman with muscular dystrophy, age 23, Argentina.

<sup>61</sup> Gina Rose, a woman with a visual impairment, age 37, the Philippines.

<sup>62</sup> Gwen, a non-binary autistic person, age 24, France.

<sup>63</sup> A non-binary autistic person with post-traumatic stress disorder, the Netherlands.

<sup>64</sup> Linda, a woman with an intellectual disability, age 41, New York. U.S.

<sup>65</sup> Alex, a non-binary, autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S.

<sup>66</sup> A woman with physical disabilities, age 26, New York, U.S.

<sup>67</sup> Karina, a woman with mental disabilities, age 41, U.S.

Others classified rationing as a form of discrimination or eugenics.

- A non-binary autistic person expressed that rationing is an "excuse to perform eugenics on disabled individuals. I don't think there's any way to approach medical rationing in an ethical manner."68
- One respondent noted in particular that rationing assumes that persons with disabilities live lives of less value: "I think I am personally at less risk of being excluded than some of my disabled peers, but it still concerns me that there seems to be some biased assumptions that disabled people automatically have lower quality of life, or are automatically less likely to survive Covid-19, rather than judging on a case by case basis."

Two respondents further expressed distrust of healthcare providers when it came to rationing, likely resulting from the medical model of disability, which assumes that disability is a condition to be fixed and that persons with disabilities have a lower quality of life.69

- One respondent highlighted that some persons with disabilities may either avoid treatment or try to hide their disability: "I see disabled people in social media talking about how they are scared to go to the hospital for any reason and making plans to try to hide some of their disabilities or medical diagnoses in order to avoid doctors putting a DNR [Do Not Resuscitate] in their record without their consent."70
- Another respondent expressed concern that new ethical protocols might allow doctors and others to only consult with family and a patient's chart when making medical decisions about things like respirators in critical cases, and in particular that a patient's own advance directive may not be accessible during these decisions.71

#### **Meeting Basic Needs**

Women, girls, non-binary, trans, and gender non-conforming persons with disabilities are experiencing significant barriers to meeting their basic needs due to COVID-19.

All persons have the right to an adequate standard of living, which includes the right to have their basic needs met, such as those related to water, hygiene, food, and shelter.72 Indeed, ensuring that people have access to essential underlying determinants of health (including food, water, shelter, and essential medicines) is also part of the core minimum obligations that States must meet to protect the right to health.73 Women and persons with disabilities also have a right to social protection without discrimination, and States must in particular ensure that women and girls with disabilities have access to social protection measures to ensure an adequate standard of living. 74 Persons with disabilities further have a right to live in the community, including "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community."75 As the CRPD Committee has found, although the right to access support services to live in the community is a right of progressive realization. States cannot implement retrogressive measures with respect to this right unless they are

<sup>68</sup> A non-binary autistic person, age 30, U.S.

<sup>69</sup> See, e.g., Women Enabled International, Abortion and Disability: Towards an Intersectional Human Rights-Based Approach 7 (2020), https://womenenabled. org/pdfs/Women%20Enabled%20International%20Abortion%20and%20Disability%20-%20Towards%20an%20Intersectional%20Human%20 Rights-Based%20Approach%20January%202020.pdf.

<sup>70</sup> Andrea, age 50.

<sup>71</sup> Marcela, a woman with a psychosocial disability, age 59, Chile, translated from Spanish {: "...Nos preocupa que se hable de un protocolo ético de la mesa social, cuando los servicios públicos solo consultan la familia y ven la ficha clinca de los pacientes, y que esto sea ético pero, que nadie tenga información accesible sobre declaraciones de voluntad anticipada por ejemplo para el acceso de respiradores mecánicos en casos críticos").

<sup>72</sup> ICESCR, supra note 7, art. 11.

<sup>73</sup> ESCR Committee, Gen. Comment No. 14, supra note 8, para. 43.

<sup>74</sup> CEDAW, supra note 9, art. 13; CRPD, supra note 9, art. 28.

<sup>75</sup> CRPD, supra note 9, art. 19.

"temporary, necessary and non-discriminatory" while respecting the core obligations of this right, including the right to make decisions for oneself about where and how to live.77

Many persons with disabilities require support for basic tasks of independent living, including preparing and consuming food, personal hygiene, and leaving their homes. Other persons with disabilities may require support to navigate inaccessible environments or to communicate with others, including healthcare providers. For women, girls, non-binary, trans, and gender non-conforming persons with disabilities, these support services may be the difference between being able to access needed health services, including sexual and reproductive health services and COVID-19 response services, and suffering alone at home. If a woman with a disability has to instead rely on a partner or family member to undertake these tasks, that dependence makes them vulnerable to violence and abuse. 78 Outside services provide a network of support for women with disabilities that allow them independence and give them an avenue to leave violent home environments, particularly important in times of increased isolation and heightened violence.

Furthermore, women, girls, non-binary, and gender non-conforming persons with disabilities already disproportionately live on the brink of extreme poverty, due to significant barriers to accessing education based on gender and disability discrimination, as well as lower rates of formal employment, reliance on informal sectors of work, and lower rates of pay than men with disabilities or other women.<sup>79</sup> They also have highercosts of living than many others, due to disability-related needs (including assistive devices, healthcare, support services, etc.)80 and gendered expectations and needs (including related to healthcare, higher costs for hygiene items, items for menstrual hygiene, etc.).81

According to Survey respondents, lockdowns, shelter-in-place orders, and other restrictions on movement during the COVID-19 crisis have had a significant impact on their ability to meet basic needs, achieve an adequate standard of living, and live independently. This is because many respondents had lost their sources of income. their support services were no longer available, accessible transportation was shut down or became inaccessible, and social distancing rules and recommendations made members of the public or family members unable or unwilling to help them.

#### **Loss of Employment and Income**

The majority (57) Survey respondents shared that their access to employment and income had been impacted by the COVID-19 crisis, including several who had lost their jobs or had to take sick leave due to the pandemic, 82 who had found the job market was not friendly to them obtaining other employment,83 and/or who were having financial hardships as a result of the pandemic.84 These circumstances can make meeting basic needs particularly difficult.

Lisa, an autistic woman in the U.K, reported that: "I lost everything. I left my former job in the beginning of February and started to work on a freelance basis when everything collapsed. I am not entitled for government help and also wouldn't know how to apply for it."85

<sup>76</sup> CRPD Committee, General Comment No. 5 on living independently and being included in the community, para. 43, U.N. Doc. CRPD/C/GC/5 (2017).

<sup>78</sup> See, e.g., Matthew J. Breiding & Brian S. Armour, The association between disability and intimate partner violence in the United States, 25(6) Ann. Epidemiol. 455 (2015), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4692458/

<sup>79</sup> See, e.g., Women Enabled International, Submission on the Rights of Women with Disabilities in the World of Work to the Working Group on the issue of Discrimination against Women in Law and in Practice (Aug. 30, 2019), https://womenenabled.org/pdfs/WEI%20Submission%20 Women%20with%20Disabilities%20and%20the%20World%20of%20Work%20August%2030,%202019.pdf.

<sup>80</sup> For instance, it costs 25% more to live with a disability in the UK than without one, considering additional expenses for support services and health care. Papworth Trust, Disability in the United Kingdom 2014: Facts and Figures 14 (2014), http://www.papworthtrust.org.uk/sites/default/files/ UK%20Disability%20facts%20and%20figures%20report%2020 14.pdf.

<sup>81</sup> See, e.g., Aimee Pichi, "The doubly high cost of being female," CBSNews.com, Apr. 7, 2018, https://www.cbsnews.com/news/ the-doubly-high-cost-of-being-female/.

<sup>82</sup> Caitlin, an autistic woman, age 22, Australia; Estefania, a blind woman, age 26, Panama; Lisa, an autistic woman, age 30, U.K.; Dorothy, a woman with quadriplegia, age 64, South Africa; A woman with muscular dystrophy, age 33, the Netherlands.

<sup>83</sup> Estefania, a blind woman, age 26, Panama; Andrea, age 50.

<sup>84</sup> A Deaf woman, age 44, Brazil; Daisy, a non-binary person with ME, age 27, U.K.; Rachel, a woman with a physical disability, age 61, Malawi; Vitoria, a woman with fiscia, age 35, Brazil; A woman with severe physical disability, age 25; Nanyunja, a woman with a physical disability, age 30, Uganda; Asia, a woman with a physical disability, age 30, Jordan; Abia, a woman with a physical disability, age 34, Pakistan; Susan, a woman with paraplegia, age 73, U.S.

<sup>85</sup> Lisa, an autistic woman, age 30, U.K.

- A Deaf woman in Nepal noted that her entire family was dependent on her salary. She described that losing her job has meant that she has "to borrow daily food and vegetables from the stores" near her house. Fortunately for her, these stores have agreed to allow her to pay them after she gets her job back after the lockdown.86
- Angelica, a woman with a physical disability from El Salvador, shared her fears about job loss and finances: "I am very afraid of being left without my financial income due to the loss of my job or that my husband will not have access to his money and will not have money for food and basic services."87
- Linda, a woman with an intellectual disability from the U.S. state of New York, shared the uncertainty she was feeling about being re-hired by a small business: "My coffee shop job is a small business. They may change it to just one person who has to open it by yourself. I might have to get rehired. They might call me back. There is a possibility I may not be able to come back. Plus, I am part time and I live at a residence [group home] so I can't make much money."88

Many women, non-binary, gender non-conforming, and trans persons with disabilities are entrepreneurs and freelancers or work in informal arrangements, and those respondents who identified as such expressed particular difficulties related to work and income.89

- ▶ An autistic woman with various psychiatric and learning disabilities in the U.S. state of Washington stated that "[M]y spouse and I opened our own small business before mandatory shutdowns and do not qualify for any assistance because we were open less than a year and exclusively served clients over 18. (We are a tattoo shop)."90
- ▶ A non-binary sex worker from Amsterdam who is chronically ill and autistic explained "I lost all my income because my job was forbidden but I'm not compensated for it so that absolutely sucks."91
- Karen, a woman from the U.S. with multiple disabilities, shared: "I'm an artist. It's impossible now to show my work. An exhibition I was supposed to be in was canceled."92
- Jenny, a woman with a physical disability in El Salvador, shared: "I only feel affected in my financial situation, since I am an entrepreneur and my business has been affected, because I cannot sell my artistic paintings or my crafts. I also live with my parents, who are older adults, who also do not have formal employment, nor a pension. For this aspect I am concerned and affected."93
- A 48-year-old woman with psychosocial disabilities described in detail how freelance work does not come with the same social security as other forms of employment in her country: "I am an independent consultant and am very lucky to have work at the moment. However, if it dries up due to the on-going economic situation, I will not be eligible for benefits offered by the government. It's complicated, but the supports for self-employed have too many restrictions, and I fall through the cracks since I haven't been self-employed long enough. Also, you cannot access to benefits if you earned above a certain amount which is based on past annual earnings for self-employed that is not there for those in regular employment. So, the government feels that self-employed that earn above a certain salary do not need assistance but waged workers that earn above that same salary do need assistance. It is unequal."94

<sup>86</sup> A Deaf woman, age 43, Nepal.

<sup>87</sup> Angelica, a woman with a physical disability, age 53, El Salvador, translated from Spanish ("me causa mucho temor quedarme sin mis inresos económicos por la pérdida del trabajo o que mi esposo no tenga el acceso a su dinero y no contar con el dinero para la alimentación y pago de los servicios básicos.").

<sup>88</sup> Linda, a woman with an intellectual disability, age 41, New York. U.S.

<sup>89</sup> Aver, a woman with a physical disability, age 34, Nigeria [cake orders cancelled]; Jenny, a woman with physical disabilities, age 45, El Salvador; a woman with psychosocial disabilities, age 48; an autistic woman with various psychiatric and learning disabilities, U.S.; a non-binary autistic person who is chronically ill, the Netherlands.

<sup>90</sup> An autistic woman with various psychiatric and learning disabilities, U.S.

<sup>91</sup> A non-binary autistic person who is chronically ill, the Netherlands.

<sup>92</sup> Karen, a woman with multiple disabilities, age 57, U.S.

<sup>93</sup> Jenny, a woman with physical disabilities, age 45, El Salvador.

<sup>94</sup> A woman with psychosocial disabilities, age 48.

For those not employed, accessing social protection measures has also sometimes been challenging.95

- A respondent with paralysis from El Salvador stated that "The government is giving an economic subsidy, for people who are not working or who have affected our economy, but I have not yet benefited from this."96
- A Deaf woman from Brazil stated "I will probably not be able to get access to basic emergency universal income, to be paid by the Brazilian government, because access to it is based on the calculation of family income and not individual income. This does not solve my financial problems, because monthly I have to pay individual bills."97
- At least one individual also identified that her pension had suffered as a result of COVID-19, meaning that "I will probably not have anything to live off of and very little time to recover this money, given my age."98

Those who maintained employment but were trying to work from home also encountered challenges.99 For instance, a 26-year-old woman from the U.S. with a physical disability explained that the pandemic has triggered mental health issues, making work from home difficult, 100 a situation that might put her long-term employment at risk.

#### **Loss of Support Services. Public Services. Assistive Devices.** and Assistance from the Community

At least 32 Survey respondents indicated that the COVID-19 crisis has affected their ability to access needed disability-related support services. 101 This is because these individuals themselves were not permitted to leave their homes, or because support services were not able to come to them. This has included, for instance, a decrease in access to technical assistance, personal assistance, wheelchair replacement and repair, and accessibility services such as Sign Language interpreters. 102 as well as a decrease in access to public transportation. 103

- A woman from Serbia with a physical disability noted in particular the barriers that restrictions on movement can have related to support services- "Our government passed a law banning movement ... but did not consider persons with disabilities, the movement of personal assistants, those PWD [persons with disabilities] who live alone or with parents over 65 years. Only after a month or so they made the decision that certain groups could get movement permits but this procedure took several days."104
- A respondent from Uganda who is also herself a service provider for persons with disabilities specifically highlighted the lack of physical access to her office and expressed concern over the fact that the police were arresting individuals who stepped out for work, 105 which would include care providers.

A woman with post-traumatic stress disorder, age 48, Tennessee, Nanyunia, a woman with a physical disability, age 30, Uganda; Joyce, a woman with physical disabilities, age 55, Canada.

Jenny, a woman with physical disabilities, age 45, El Salvador. 96

A Deaf woman, age 44, Brazil.

A woman with psychosocial disabilities, age 48. 98

Lyness, a woman with physical disabilities, age 54, Malawi, Dorothy, a woman with quadriplegia, age 64, South Africa (clients can't come over), a woman from Uganda; Namugabwe, a person with a psychosocial disability (cannot access workplace due to reduced transportation); Karina, a woman with mental disabilities, age 41, U.S.; a woman with depression, age 65, Indiana, U.S.

<sup>100</sup> A woman with a physical disability, age 26, U.S.

<sup>101</sup> See, e.g., Pratima, a woman with a physical disability, age 39, Nepal; Nanyunja, a woman with a physical disability, age 30, Uganda; an autistic woman with various psychiatric and learning disabilities, Washington. U.S.; Karina, a woman with mental disabilities, age 41, U.S.; Barbara, a woman with a physical disability, age 71, Indiana, U.S.

<sup>102</sup> See, e.g., Marilene, a woman with a hearing impairment, age 46, Brazil; Rachel, a woman with a physical disability, age 61, Malawi; A Deafblind woman, age 45; a woman with a psychosocial disability, age 39, Ireland; Lyness, a woman with physical disabilities, age 54, Malawi; a woman with paraplegia, age 56; Aver, a woman with a physical disability, age 34, Nigeria; a woman with psychosocial disabilities, age 48; Lisa, an autistic woman, age 30, U.K.; Alex, a non-binary, autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S., Namugabwe, a person with a psychosocial disability (access to support groups), Line 42, Abia, a woman with a physical disability, age 34, Pakistan; Caroline, a woman with a physical disability, age 48, France; a woman with depression, age 65, Indiana, U.S.; Cassandra, a woman with diabetes and a compromised immune system, age 25, U.S.

<sup>103</sup> Daisy, a non-binary person with ME, age 27, U.K.; Caitlin, an autistic woman, age 22, Australia; Estefania, a blind woman, age 26, Panama; Asia, a woman with a physical disability, age 30, Jordan; A woman with a physical disability, age 43, Serbia (dependent on husband now and restricted to neighbourhood), Joyce, a woman with physical disabilities, age 55, Canada.

<sup>104</sup> A woman with a physical disability, age 43, Serbia.

<sup>105</sup> A woman from Uganda.

A woman with chronic illness reported that she has decided to allow her mother to start coming to her house again to provide assistance: "Up till now my mother couldn't come to our place to help out in the house as she usually did every two weeks, but we have now decided it is probably safe for her to come as we both have been isolating for a few weeks now."106

Respondents further identified that lack of access to wheelchairs and other needed assistive devices has been a significant issue during this crisis.

- A 33-year-old woman from the Netherlands with muscular dystrophy explained that "I was in the process of getting support from the rehabilitation centre for new assistive devices and other necessary solutions for my current physical challenges; this process is now on hold because the rehabilitation centre is closed for external patients (to help corona patients from ICU's and to avoid spreading the virus). In addition, I was in the process of applying for personal assistance for daily activities at home (transfer bed-wheelchair, shower, etc). This is also on hold because having carers coming in and out of the house is too risky - and there are no protection materials or guidelines provided by the government for home care. Until all this is arranged, I cannot return to my full-time job (I'm currently on sick leave)."107
- A woman with chronic illness noted: "I was in the process of getting a new wheelchair but this will take more time now."108

A few respondents identified that the stress of COVID-19 with family members or friends meant that requests for assistance were harder to make:109

- One person who wished to remain anonymous described that, because of an argument with a family member, that family member would no longer deliver her medications to her. 110
- Rosario, a woman with muscular dystrophy in Argentina, also shared that: "The moods and emotions of other people determine when they help someone, and in those moments where panic and anguish prevail, any request, whether it be 'I want to go to the bathroom,' can trigger a family conflict."111

Social distancing policies in particular have impacted the ability of some respondents to meet their basic needs or to access community.

- A young blind woman in Argentina described how this lack of assistance made it hard for her to meet her basic needs on her own and has made her more dependent on family: "My family has to do the shopping because I have to cross an avenue to go to any business and nobody comes to help me because they want to avoid contact."112
- Andrea, a visually impaired woman in Argentina, expressed fear that her independence would be restricted because of social distancing: "Although the circulation of people who must assist people with disabilities is allowed, my fear is that many people with visual disabilities lived an autonomous life, although for that we needed help from other people to cross the streets. But that help would not meet the social distancing required in this emergency, so I suppose that our independent life will be restricted until the pandemic lasts."113

<sup>106</sup> A woman with chronic illness, age 34.

<sup>107</sup> A woman with muscular dystrophy, age 33, the Netherlands.

<sup>108</sup> A woman with chronic illness, age 34.

<sup>109</sup> A woman with physical paraplegy, age 56; Barbara, a woman with a physical disability, age 71, Indiana, U.S.; A non-binary person with depression, age 25, U.S.

<sup>110</sup> Survey from a person who wished not to be identified.

<sup>111</sup> Rosario, a woman with muscular dystrophy, age 23, Argentina.

<sup>112</sup> Celeste, a blind woman, age 19, Argentina, translated from Spanish ("Mi familia es quien tiene que hacer las compras porque yo para ir a cualquier negocio tengo que cruzar una avenida y nadie se acerca a ayudar para evitar el contacto").

<sup>113</sup> Andrea, a woman with a visual disability, age 33, Argentina, translated from Spanish ("Si bien se permite la circulación de personas que deban asistir a personas con discapacidad, mi temor es que muchas personas con discapacidad visual llevábamos una vida autónoma, aunque para eso necesitábamos ayuda de otras personas para cruzar las calles. Pero esa ayuda no cumpliría con el distanciamiento social requerido en esta emergencia, por lo que supongo que nuestra vida independiente se verá restringida hasta tanto dure la pandemia").

Another respondent reported that: "This has really affected me as a deafblind individual in terms of how we the deafblind communicate, it has really affected my physical, emotional and psychological [well-being]."114

Many respondents highlighted that decreased support services meant decreased access to the outdoors, community, and social life, and some particularly noted the impact of such isolation on their mental health. Caitlin, an autistic woman from Australia, explained that this may lead to long-term loss of social skills. Gwen, a non-binary respondent stated that their access to support groups and community they had relied on within the non-binary and autistic community to maintain mental health had further been cancelled.

Abia, a woman with physical disabilities from Pakistan, shared: "[W]ithout the support of personal assistant its disturbing all the activities. creating emotional & psychosocial problems." 118

This decreased access to services and the community has had an impact on meeting even the most basic needs, including those related to food, sanitation, and hygiene, as well as social and psychological needs.<sup>119</sup>

- ► As Rosario, a woman with muscular dystrophy in Argentina, explained: "Before, I had a person who helped me change and bathe every day. With this situation the service is not available and I feel powerless to handle my own hygiene." 120
- ► Changes to public transportation were a particular issue for many. Lyness, a person with a physical disability from Malawi, noted: "Our minister of transport announced that the bus fares have been doubled and those who can not afford should walk without considering persons with disabilities." Other respondents highlighted a decrease in ability to access groceries, including as a result of cuts in public transportation. 122
- ▶ A woman from Nepal emphasized the decreased access to sanitary products and services as a result of the lockdown, including the lack of supports to access these goods.¹²³
- ▶ A woman from Uganda stated "I fear I may run out of food. I was not prepared for this. The government is distributing food only in the city centre." 124
- ▶ Lisa from London expressed how inconsiderate people are at this time, which makes meeting needs for people like her more difficult: "[T]he situation showed that people started to fight on their own pushing each other in the supermarket to get the last milk etc. If you are a vulnerable person who has problems with fighting your way through and standing up for yourself you get treated like a door mat. We are simply forgotten. I decided that I won't hoard food so that other people have a chance as well the result was that I eat a whole week the few toasts which I had left in the house because the aisles in the supermarkets were empty." 125

At least two respondents reported that the decrease in access to services or assistance from the public made them more reliant on intimate partners or other family members. As noted above, this dependence could open

<sup>114</sup> A Deafblind person.

Rachel, a woman with a physical disability, age 42, Illinois, U.S.; Vitoria, a woman with fiscia, age 35, Brazil; A woman with physical paraplegy, age 56; Caitlin, an autistic woman, age 22, Australia (concerned about effect of being home all the time on others around her); a woman with post-traumatic stress disorder, age 48, Tennessee, U.S.; a woman with severe physical disability, age 25; Karen, a woman with multiple disabilities, age 57, U.S.; Caroline, a woman with a physical disability, age 48, France; Cassandra, a woman with diabetes and a compromised immune system, age 25, U.S.; a non-binary person with depression, age 25, California, U.S.

<sup>116</sup> Caitlin, an autistic woman, age 22, Australia.

<sup>117</sup> Gwen, a non-binary autistic person, age 24, France.

<sup>118</sup> Abia, a woman with a physical disability, age 34, Pakistan.

<sup>119</sup> A woman with a disability resulting from polio, age 44, Nepal; Pratima, a woman with a physical disability, age 39, Nepal.

<sup>120</sup> Rosario, a woman with muscular dystrophy, age 23, Argentina, translated from Spanish ("Antes tenía una persona que me asistía a cambiarme y bañarme todos los días. Con ésta situación se hace imposible el servicio y me siento impotente frente a mi propia hygiene.").

<sup>121</sup> Lyness, a woman with physical disabilities, age 54, Malawi.

<sup>122</sup> Daisy, a non-binary person with ME, age 27, U.K.; Caitlin, an autistic woman, age 22, Australia; Estefania, a blind woman, age 26, Panama; Asia, a woman with a physical disability, age 30, Jordan; A woman with a physical disability, age 43, Serbia (dependent on husband now and restricted to neighbourhood), Joyce, a woman with physical disability, age 55, Canada.

<sup>123</sup> A woman with a disability resulting from polio, age 44, Nepal.

<sup>124</sup> A woman from Uganda.

<sup>125</sup> Lisa, an autistic woman, age 30, U.K.

<sup>126</sup> A woman with a physical disability, age 43, Serbia (dependent on husband now and restricted to neighbourhood); Celeste, a blind woman, age 19, Argentina, translated from Spanish ("Mi familia es quien tiene que hacer las compras porque yo para ir a cualquier negocio tengo que cruzar una avenida y nadie se acerca a ayudar para evitar el contacto").

them up to violence or abuse by these individuals, as it changes the power dynamic between these individuals and exacerbates stress.

Without the ability to meet basic needs, persons with disabilities are more vulnerable to being placed in longterm residential care institutions, in violation of their right to independent living. Women, girls, non-binary, and gender non-conforming persons with disabilities may be especially vulnerable to institutionalization, as they may lack employment or other means of support to live in the community and may also receive less support from family than men with disabilities. 127 While institutionalized, these individuals are also more vulnerable to violence and abuse as well as to COVID-19.

Due to the limitations of this initial survey, it did not reach persons with disabilities living in institutions. However, one survey respondent expressed particular worry about the situation of women with disabilities in institutions: "I am distressed for women with mental disabilities deprived of their liberty in public psychiatric facilities, overcrowded and forced to use immunosuppressive drugs in unhygienic settings, as well as in nursing homes and children's homes or those in jails."128

Linda, a woman with an intellectual disability living in a small group home of 14 people in the U.S. state of New York identified a practice she thought \worked well to ensure that those living in the group home still had the support they needed while also staying safe from COVID-19: "I have the help I need. The staff are doing quarantine and sleep here for 14 days. I think it is good because it will be less germs. I don't mind that they sleep at the house because we need assistance."129

#### **Ensuring Freedom from Violence**

Women, girls, non-binary, trans, and gender non-conforming persons with disabilities are at greater risk of violence due to COVID-19.

Women, girls, non-binary, trans, and gender non-conforming persons with disabilities have the right to be free from violence, exploitation, and abuse. As the CEDAW Committee has recognized, the right to be free from genderbased violence in particular is "an obligation of an immediate nature; delays cannot be justified on any grounds, including economic, cultural or religious grounds."130 States also have an obligation to exercise due diligence related to violence committed by non-State actors, including intimate partners or family members, including an obligation to "take all appropriate measures to prevent, as well as to investigate, prosecute, punish and provide reparations for, acts or omissions by non-State actors that result in gender-based violence..."131

Home may be a safe place for most, but for many women, girls, non-binary, trans, and gender non-conforming persons with disabilities, their homes are a place of fear. Women and girls with disabilities experience violence from partners and family members at least two to three times the rate of other women, <sup>132</sup> and during lockdowns, shelter in place orders, and other times of mandatory or recommended isolation, these individuals will be even less able to escape violence, particularly if their usual supports are not available to them. 133 Institutionalized persons with disabilities are at further risk of violence due to their isolation, 134 which increases when visitors and monitors may not be allowed in.

<sup>127</sup> See, e.g., U.N. Commission on Human Rights, Women and adequate housing: Study by the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, Miloon Kothari, para. 64, U.N. Doc. E/CN.4/2005/43 (2005), https://www.un.org/ womenwatch/enable/E-CN4-2005-43\_Housing.pdf.

<sup>128</sup> Marcela, a woman with a psychosocial disability, age 59, Chile.

<sup>129</sup> Linda, a woman with an intellectual disability, age 41, New York. U.S.

<sup>130</sup> CEDAW Committee, General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19, para. 21, U.N. Doc. CEDAW/C/GC/35 (2017).

<sup>132</sup> United States Agency for International Development (USAID), Untied States Strategy to Prevent and Respond to Gender-based Violence Globally 7 (Aug. 10, 2012), http://www.state.gov/documents/organization/196468.pdf. It is worth noting that no global data exists on the incidence of such violence, and studies draw on different sources of data.

<sup>133</sup> Emma Pearce, Disability Considerations in GBV Programming during the COVID-19 Pandemic (Mar. 2020), http://www.sddirect.org.uk/ media/1889/gbv-aor-research-query\_covid-19-disability-gbv\_final-version.pdf.

<sup>134</sup> WORLD HEALTH ORGANIZATION & WORLD BANK, WORLD REPORT ON DISABILITY 59 (2011), https://www.who.int/disabilities/world\_report/2011/report/en/.

Most respondents to the Survey reported that COVID-19 and the government and healthcare responses had not posed a threat to their personal safety and that they did not feel at increased risk of violence at home or in their communities. However, 22 survey respondents did report fear for their personal safety, and some identified particular issues impacting that safety:

- ▶ Alex, a person with multiple disabilities in the U.S. state of Texas, reported: "My family is emotionally abusive, and I am trapped in a house with them. I am also immunocompromised and am in danger every time someone leaves the house, in addition to being trans in a very transphobic family. This is an incredibly dangerous situation for me, and my mental health has suffered greatly as a direct result of the pandemic and respective quarantine measures."135
- Lisa, an autistic woman in the U.K, reported: "I live in a camper van at the moment and try to keep safe as a lot of people in my former area just getting annoyed and aggressive with each other. I can't deal with the tension between the people around me."136
- ▶ A woman with psychiatric disabilities from the U.S. state of Tennessee expressed fear from a particular individual due to the crisis, although she did not specify who: "There has been some reluctance on their part to accept what is happening because he has control issues and feels angry he has to live by someone else's timeline or time-table."137

Superstition resulting from stigma and discrimination against persons with disabilities in some contexts has also been exacerbated by COVID-19, which may put women, girls, non-binary, trans, and gender non-conforming persons with disabilities at particular risk of violence.

- ▶ A person who wished not to be identified shared: "[B]ecause of lack of melanin people are speculating that I can easily contract COVID 19."138
- Sabrina, a survey respondent from Colombia, shared that: "I have had to go out a couple of times for groceries and to the bank and in some of the lines it has happened to me that other people yell at me because they think that I should not go out or that I am a carrier of the virus just because I have a disability."139

As noted above, several respondents also reported risk factors for violence and personal safety including increased dependence on others to meet basic needs and financial obligations or the inaccessibility of information about the crisis.140

- ▶ The leader of an organization working with women with disabilities in Malawi reported particularly fear for some in her community: "My major concern are the women in rural areas who are vulnerable, with the lockdown, it means they are financially handicapped, they cannot feed themselves, so chances of sexual abuse will be high just for them to have bread and butter for the day."141
- In response to the question on personal safety, one woman also reported: "We are very worried because Deaf persons with disabilities are not getting information given by ministry due to lack of sign language interpreters."142

<sup>135</sup> Alex, a non-binary, autistic person with physical, emotional, and mental disabilities, age 23, Texas, U.S.

<sup>136</sup> Lisa, an autistic woman, age 30, U.K.

<sup>137</sup> A woman with psychiatric disabilities, age 48, Tennessee, U.S.

<sup>138</sup> Pamela, a woman, age 42.

<sup>139</sup> Sabrina, a Deaf woman with a physical disability, age 34, Colombia, translated from Spanish ("He tenido que salir un par de veces por víveres y al banco y en algunas de las filas me ha sucedido que otras personas me griten porque creen que no debería salir o que soy portadora del virus sólo por tener discapacidad.").

<sup>140</sup> See above, Findings: Meeting Basic Needs.

<sup>141</sup> Rachel, a woman with a physical disability, age 61, Malawi.

<sup>142</sup> A person with physical disabilities.

#### **Conclusions and Recommendations**

Women, girls, non-binary, trans, and gender non-conforming persons with disabilities are at risk during the COVID-19 crisis of losing access to healthcare, being unable to meet their basic needs, and of experiencing violence, and that risk is heightened because of the discrimination they experience due to their disability and gender or gender identity. In order to prevent further abuse, States and healthcare actors must ensure that the needs, priorities, and voices of these individuals are included in the government and health responses to the COVID-19 crisis at the local, national, regional, and international levels. As Estefania, a blind woman from Panama, wrote, "I believe that governments should implement programmes aimed at women with disabilities who are going through this pandemic situation."143

#### **Recommendations**

#### **To States:**

- Involve women, girls, non-binary, trans, and gender non-conforming persons with disabilities in planning for and implementation of the COVID-19 government and healthcare responses.
- lssue specific guidance to healthcare providers on ensuring rights-based care during the COVID-19 crisis that makes clear that discrimination on prohibited grounds, including at the intersection of gender and disability, is not permitted.
- Urgently adopt social protection measures—including income supplementation, rent subsidies and eviction moratoriums, food subsidies, and free clean water and hygiene measures, including menstrual hygiene—to fill the gap in income for all persons so that they can meet their basic needs. Ensure those who worked as freelancers, entrepreneurs, or in the informal sector or who received other types of income support are eligible for these measures.
- Undertake particular efforts to reach women, girls, non-binary, trans, and gender non-conforming persons with disabilities with social protection measures, including through campaigns that provide information in a variety of accessible formats, and ensure that social protection goes directly to these individuals rather than to families or partners.
- Classify disability-related support services, sexual and reproductive health services, and gender-based violence services as essential services during COVID-19 lockdowns, stay-in-place orders, or other restrictions on movement and ensure a streamlined process for obtaining any needed permits for movement for these service providers.
- Continue or initiate efforts to tackle stereotypes and stigma about gender and/or disability, as a means of protecting individuals from violence during this crisis and ensuring they get the community supports and healthcare they need without discriminatory rationing.
- Ensure that access to disability-accessible public transportation is maintained and at reasonable cost.
- Ensure that lockdowns, stay-at-home orders, and other limits on movement specifically allow for people to leave their homes to escape violence, including physical, sexual, emotional, psychological, and financial violence.

#### To U.N. Agencies:

- ▶ Ensure that all guidance provided to States recognizes the particular impact of COVID-19 on women, girls, non-binary, trans, and gender non-conforming persons with disabilities and takes a twin-track approach to recommending action, ensuring that these individuals are included in mainstream response efforts and that responses are targeted specifically at the intersection of gender and disability.
- ▶ Ensure that women, girls, non-binary, trans, and gender non-conforming persons with disabilities are included in information related to both gender and disability that is provided to States about ensuring an inclusive and human rights-based response to COVID-19.

#### **To Healthcare Systems:**

- Involve women, girls, non-binary, trans, and gender non-conforming persons with disabilities in planning for and implementation of new protocols for providing care.
- Provide accessibility supports for virtual or remote medical appointments, including Sign Language interpretation.
- ▶ Prioritize marginalized groups, including women, girls, non-binary, trans, and gender non-conforming persons with disabilities, in the provision of all forms of available care, including mental healthcare and access to needed medications.
- ▶ Recognizing the likely increase in violence due to COVID-19, continue or initiate efforts to screen patients for violence when they access health services.

#### To Violence Service Providers: 144

- ► Ensure that communications around ongoing services for victims of violence is available in accessible formats, including Sign Language, Braille, and plain language, and distributed in a variety of ways, including through radio, television, in hard copy, on posters and public displays, and on social media.
- ▶ Undertake targeted measures to reach out to women, girls, non-binary, trans, and gender non-conforming persons with disabilities with information about services during COVID-19, including by reaching out to disability support service providers or other civil society organizations (including organizations of women with disabilities) that are most likely to be in touch with these individuals apart from their family or intimate partners during the crisis.
- ▶ Ensure that shelters are physically accessible, welcoming, and will allow women, girls, non-binary, trans, and gender non-conforming persons with disabilities to bring support animals.

For more information on gender-based violence services during the COVID-19 crisis, see MADRE, Women Enabled International, et al, From Global Coordination to Local Strategies: A Practical Approach to Prevent, Address and Document Domestic Violence under COVID-19 (Apr. 2020), https://womenenabled.org/pdfs/MADRE%20Domestic%20Violence%20Under%20COVID-19%20Briefing%20Paper%204-21-2020.docx.



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Women Enabled International advances 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. Women Enabled International envisions a world where women and girls with disabilities claim human rights, act in solidarity and lead self-determined lives.







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