# Submission to Mrs Dubravka Šimonović, Special Rapporteur on Violence against Women, its causes and consequences

**Mistreatment and violence against women during reproductive health care with a focus on childbirth**

## The Making It Work Gender and Disability Project

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## Humanity & Inclusion

 The Making It Work – Gender and Disability project, under Humanity and Inclusion’s Protection and Risk Reduction Division, fights violence against women and girls with disabilities in Africa. It does so by supporting partner organizations, which are women’s rights and disabled women organizations, and by supporting their advocacy work, using well-documented good practices as evidence. In 2019, Making It Work has a partnership with 17 grassroots organizations in Burundi, Kenya, Malawi, Mali, Nigeria, Rwanda and Uganda.

This submission combines observations from the MIW team made during visits to the partners and direct contributions from four of them:

* MUbende Disabled Women’s Association (MUDIWA), Uganda
* Organisation pour un Développement Intégré au Sahel (ODI Sahel), Mali
* United Disabled Persons of Kenya (UDPK), Kenya
* Union des Personnes Handicapées du Burundi (UPHB), Burundi

Women and girls with disabilities are twice as likely to experience domestic violence and other forms of sexual and gender-based violence as non-disabled women[[1]](#footnote-1). The intersectionality of gender and disability significantly increases their vulnerability and exposure to all kind of mistreatment and violence, including those happening during sexual and reproductive health care and childbirth. The main attention points around this issue have been identified as follow:

1. In response to the Special Rapporteur’s first question:

***Please indicate whether in your country there are cases of mistreatment and violence against women during reproductive health care, particularly facility-based childbirth. If so, please specify what kind of cases and describe your country’s response and any good practices, including protection of human rights***;

1.1 **Mistreatment of women and girls with disabilities during SRH care, childbirth, prenatal and postnatal care due to stigma**

While the UN Committee on the Rights of Persons with Disabilities has emphasized **the rights of women with disabilities to found a family and raise children**[[2]](#footnote-2), many women with disabilities are often stigmatized by health practitioners and their communities during pregnancy and childbirth. Families as well are often unsupportive of their pregnancies. There is a strong prejudice toward them having children as they are considered unfit for motherhood. Women with disabilities often undergo **verbal, psychological and physical violence** by health practitioners during childbirth, while not accessing prenatal and postnatal care.

The UPHB in Burundi, reports the case of Gloria[[3]](#footnote-3) who did not have access to pre-natal care for her pregnancy. At the age of 16, her family chased her away as the pregnancy was the result of an unreported rape. Gloria expressed how she was “never being considered as a person” and how the health workers and nurses refused to help her because of her disability. They were insulting her and asked “how she dared be pregnant as she is nothing, as she has nothing”. The verbal abuse went with psychological violence and physical mistreatment as Gloria had to deliver her baby in the corridor. The baby did not survive and Gloria did not receive post-delivery care before being sent home.

MIW partners gathered during MIW Forum in March 2018 reported similar stories of women with disabilities delivering on the floor as they could not climb on labor beds. Also, another MIW partner shared that a woman was asked to deliver in the corridor as she was blind and unable to find the labor ward.

ODI Sahel in Mali, reports the case of Anita, a woman with a physical disability who was blamed for her pain by the midwife in the community health center[[4]](#footnote-4). In addition to the significant pain brought by her delivery, she was verbally abused while giving birth and recalls it as being “the worst moment of her life” because of “the pain, the aggressiveness of the staff and the guilt endured as a single woman with disabilities”. In her contribution to ODI Sahel, Anita makes a direct link between the abuse experienced at childbirth by women with disabilities and the number of them who prefer to deliver at home. **While they are aware of the increased sanitary risks brought by home-births, some still chose to do it to avoid the humiliation, shame and mistreatments**. This puts them and their baby to come at higher risk of death and permanent disability due to the lack of trained medical attendants.

Ugandan partner MUDIWA[[5]](#footnote-5) stresses the human cost of these home-deliveries by highlighting that women with disabilities are pushed in the hands of traditional birth attendants as they charge little money, are often in close proximity and because, as described above, health personnel have negative and violent attitudes. Traditional birth attendants lack the official authority to transfer patients to government hospitals and cases of women with disabilities dying during home births are frequent – although no clear data is available.

In addition to women with disabilities, mothers of babies with disabilities also undergo mistreatments “by association” as their child is perceived as “cursed”. In a survey conducted by Disability Rights International and Kenya Association for the Intellectually Handicapped[[6]](#footnote-6) on infanticide and abuse of children with disabilities in Kenya, 45% of surveyed women said that “they had been pressured to give up or kill their child. Mothers who kept their children were pressured to leave their children in an institution”. Babies with disabilities and their mothers are also neglected by health practitioners and not receiving proper post-natal care, exposing both mother and newborn to higher risks of death and illnesses.

* 1. **Mistreatment of women and girls with disabilities during SRH care and childbirth due to lack of accessible information and services**

Some women with disabilities are often not aware that what they are experiencing is violence, is abuse, and is a crime.[[7]](#footnote-7) This phenomenon is reinforced when abuse comes from health workers as they are supposed to respect a woman’s dignity and best interest. Information on what is violence and what normal sexual and reproductive health services are should be available to women with or without disabilities. If women worldwide face practical and legal barriers to SRHR services and information, for women with disabilities the challenge of **accessible information** is exacerbated.[[8]](#footnote-8)

Communication adapted to women with disabilities’ impairments (some may not speak, hear, see and others may have different understanding abilities) is lacking. The lack of information combined sometimes with low literacy levels expose them to greater risks. UDPK partner reports the case of Joi[[9]](#footnote-9), a woman with a physical disability, who was ill-advised by the medical team in her local health facility and carried her pregnancy long past the due date. She went to a local herbalist to induce the delivery; the baby did not survive.

**Health workers often lack the skills and tools to provide care to women and girls with disabilities**. Such skills and tools include being trained to sign language, using drawings to explain SRH information and options, having knowledge on informed consent and how to secure it, and on how to assist cases of women with disabilities while recognizing their agency and decision-making power. These elements are crucial for the accessibility of services. To them must also be added the **physical accessibility of services**. If the health facilities are not physically accessible to women and girls with disabilities, chances are low for them to visit and for health workers to be equipped to receive them. An access ramp being the bare minimum, there is a need for **accessible equipment at all levels of health facilities** (from the entry door to the labor table, including the bathrooms, resting area, etc.). In Uganda, MIW’s partner MUDIWA managed to have 40 accessible labor beds provided to Mubende referral hospital. At the same time, they trained health workers on the reproductive rights and special needs of women with disabilities for maternal health and on having a positive attitude towards them, as negative attitudes were documented as very frequent in Mubende District, Uganda.[[10]](#footnote-10)

MUDIWA also stresses the impact of distance in remote rural areas, where women with disabilities lack mobility devices and fail to receive treatment on time.[[11]](#footnote-11)

Although it might be at the margin of the intended report, MIW insists on mentioning practices of infanticide of baby girls with disabilities documented in Kenya by DRI and KAIH, two partner organizations of Making It Work. 6

1. In response to the Special Rapporteur’s second question:

***Please specify if full and informed consent is administered for any type of reproductive health care and if these include childbirth care;***

2.1**Mistreatment of women and girls with disabilities during SRH care and childbirth due to lack of consent.**

The question of informed consent is central for women and girls with disabilities and their sexual and reproductive health rights. To respect their rights, their legal capacity and the agency they have over their own body requires every decision to be made with their informed consent. There is a lack of recognition by health practitioners that **seeking informed consent is mandatory**. The Informed Consent Process[[12]](#footnote-12), as described below, is often ignored:

1. Providing all possible information and options to the person in a way they can understand (accessibility of information);
2. Determining if they can understand this information and/or their decisions (also referred to as “capacity to consent”); and
3. Ensuring that the decisions of the survivor are voluntary and not coerced by others (e.g., family members, caregivers or even service providers).

The consent of women and girls with disabilities for SRH care is particularly ignored by practices such as forced abortion, forced contraception and forced sterilization[[13]](#footnote-13). All of which go against **the right to be free from torture or cruel, inhuman or degrading treatment or punishment**[[14]](#footnote-14). The MIW team received many testimonies of practices of forced contraception during a field visit in Northern Uganda in April 2019.

The informed consent of women and girls with disabilities is violated as:

1. **Health practitioners and caregivers deny informed consent to women and girls with disabilities**

Oftentimes the decision-making power is removed from women and girls with disabilities by their families, care-givers and health workers as they are stigmatized. Women with disabilities are seen as “unable” to decide for themselves, unfit for motherhood or as a burden for their families. There is also the sensitive case of caregivers whose idea of “best interest” can be biased, and even used to justifying forced sterilization, forced abortion, over medication or forced contraception, notably to avoid unwanted pregnancies, bearing in mind their increased exposure to sexual violence and rape[[15]](#footnote-15).

However it can be argued that “arguments for their “best interests” often have little to do with the rights of women and girls with disabilities and more to do with **social factors**, such as avoiding inconvenience to caregivers, the lack of adequate measures to protect against the sexual abuse and exploitation of women and girls with disabilities, and the lack of adequate and appropriate services to support women with disabilities in their decision to become parents”13. As reported by UDPK in Kenya, the control over the life of women with disabilities can go as far as family members killing the baby after their birth.[[16]](#footnote-16)

1. **Health practitioners are unable to seek informed consent from women and girls with disabilities**

Whether they lack training of how to deal with informed consent in women with disabilities or face communication capacities with the women, health workers in our countries of interest are often not able to process the steps leading to informed consent; or to a decision based on the woman/girl’s best interest (if it is established that she lacks at that particular time the capacity to consent).

Health practitioners are oftentimes not used to treat women and girls with disabilities. For some types of impairments, they face significant communication difficulties and lack the capacities to overcome them: it prevents them to have a direct conversation with the patient, without the presence of a third-person (caregiver, relative). This is particularly complicated for women with mental or psycho-social disabilities.

Another issue for health workers is to properly take into account a woman with disability’s caregiver and involve them without acknowledging their power over the patient. Caregivers are likely to be often present when health workers interact with the patient which raises in the same time a confidentiality problem and does not allow for the patient or even the practitioner to make decisions that are free from coercion. Also, health workers may not even consider the possibility of having direct communication with the woman receiving care and systematically refer to the caregiver.

It is to be highlighted that women and girls with disabilities who lack capacity to consent at a particular moment should still be informed in a way they can understand and be involved as much as possible in the decision making process. Their best interest should be respected and never determined by one individual only but through a systematized process, involving first and foremost the woman herself, health practitioners from the facility, care givers and other family members, in full respect of her rights and dignity.

1. Forgotten Sisters — a Report on Violence against Women and Disabilities, S. Ortoleva and H. Lewis, Northeastern University School of Law Research Paper No. 104-2012 ( 2012). [↑](#footnote-ref-1)
2. CRPD Committee, *General Comment No. 3, supra* note *462*, at para. 45. [↑](#footnote-ref-2)
3. Union des Personnes Handicapées du Burundi, 21 year-old woman, Karusi Province ; Names have been changed to maintain confidentiality [↑](#footnote-ref-3)
4. ODI Sahel’s Contribution – 29 year-old woman, Douentza Circle, Mali ; Names have been changed to maintain confidentiality [↑](#footnote-ref-4)
5. MUDIWA’s Contribution [↑](#footnote-ref-5)
6. Disability Rights International and Kenyan Association for the Intellectually Handicapped: “Infanticide and Abuse: Killing and confinement of children with disabilities in Kenya”, September 27, 2018 <https://www.driadvocacy.org/wp-content/uploads/Infanticide-and-Abuse.pdf> [↑](#footnote-ref-6)
7. UNABU member’s testimony in Rwanda, Humanity & Inclusion. [Gender and disability intersectionality in practice: Women and girls with disabilities addressing discrimination and violence in Africa](https://www.makingitwork-crpd.org/sites/default/files/2018-06/MIW_GenderAndDisability_Report-June2018.pdf). Lyon: Humanity & Inclusion, 2018. License: Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International (CC BY-NC-ND 4.0). [↑](#footnote-ref-7)
8. UNFPA, “Women and young persons with disabilities – Guidelines for Providing Rights-Based and Gender-Responsive Services to Adress Gender-Based Violence and Sexual and Reproductive Health Rights”, 2018, p 99 [↑](#footnote-ref-8)
9. UDPK’s contribution – Names have been change to maintain confidentiality [↑](#footnote-ref-9)
10. MUDIWA, Baseline report for the study on prevention and protection of violence against women and girls with disabilities in Kassanda, Mubende District, Uganda, June 2015 [↑](#footnote-ref-10)
11. MUDIWA’s Contribution [↑](#footnote-ref-11)
12. Women’s Refugee Commission: “Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings”, Tool 9 [↑](#footnote-ref-12)
13. Human Rights Watch: “Sterilization of Women and Girls with Disabilities: A Briefing Paper” (Nov. 10, 2011) https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities [↑](#footnote-ref-13)
14. United Nations’ Universal Declaration of Human Rights, 1948, Article 5 [↑](#footnote-ref-14)
15. Advancing the access of deafblind women and girls to Sexual and Reproductive Health, VIHEMA Malawi [↑](#footnote-ref-15)
16. UDPK’s contribution, 16 year-old Ridah in Butere sub-county – Names have been changed to maintain confidentiality [↑](#footnote-ref-16)