

# Making the Invisible Visible

Why disability matters in  
violence against women  
and bodily autonomy





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# Acronyms

|              |  |
|--------------|--|
| <b>AAAQ</b>  | Availability, accessibility, acceptability and quality             |
| <b>AIDS</b>  | Acquired immunodeficiency syndrome                                 |
| <b>ANC</b>   | Antenatal care   |
| <b>CRPD</b>  | Convention on the Rights of Persons with Disabilities              |
| <b>CSE</b>   | Comprehensive sexuality education                                  |
| <b>DHS</b>   | Demographic and Health Survey                                      |
| <b>GBV</b>   | Gender-based violence  |
| <b>HIV</b>   | Human immunodeficiency virus                                       |
| <b>ICF</b>   | International Classification of Functioning, Disability and Health |
| <b>ICPD</b>  | International Conference on Population and Development             |
| <b>ID</b>    | Intellectual disability  |
| <b>IDD</b>   | Intellectual and developmental disabilities                        |
| <b>IPV</b>   | Intimate partner violence  |
| <b>LD</b>    | Learning disability  |
| <b>MICS</b>  | Multiple Indicator Cluster Survey                                  |
| <b>PNC</b>   | Postnatal care   |
| <b>SDG</b>   | Sustainable Development Goals                                      |
| <b>SRH</b>   | Sexual and reproductive health                                     |
| <b>SRHR</b>  | Sexual and reproductive health and rights                          |
| <b>STI</b>   | Sexually transmitted infection                                     |
| <b>UN</b>    | United Nations   |
| <b>UNFPA</b> | United Nations Population Fund                                     |
| <b>WG-SS</b> | Washington Group Short Set of Disability Questions                 |

# Glossary of terms

**Bodily autonomy** encompasses an individual's power and agency to make choices about their own body and future, without being subject to violence or coercion. This includes whether, when and with whom to have sex and/or become pregnant. It means the freedom to seek health care without needing permission from anyone. For more information, see the UNFPA State of World Population (2021).

**Gender-based violence (GBV)** refers to acts of or threats of violence that are perpetrated against people on the basis of their gender or their perceived gender, biological sex, as well as social and gender norms. GBV can refer to acts that "results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life", as described in the United Nations Declaration on the Elimination of Violence against Women (1993).

Gender-based violence can take a variety of forms – physical, emotional, psychological, sexual and economic – and can include violence perpetrated by intimate partners, family members, caregivers, medical or other service providers, law enforcement, military personnel, educators, employers and strangers. This violence can be against women and girls, who are and have historically been victimized by harmful gender roles. It can also be experienced by people of gender minorities, such as transgender, nonbinary, and gender nonconforming persons and men, if the violence is motivated by "socially ascribed (i.e. gender) differences between males and females" (UN, 1993).

**Informed consent** is the process of communication between a service provider and a service recipient. The service provider gives accurate, comprehensive and clear information about the services available, benefits, risks and alternatives to the service recipient in a manner and form that they understand, and with support as requested and directed by the service recipient, without threats, intimidation or inducements. The service recipient themselves voluntarily consent to services or decline them, based on this information.

**Intimate partner violence (IPV)** refers to the range of sexual, psychological and physical acts that can be used against women and young people with disabilities by a current or former intimate partner, without that person's consent. For people with disabilities, intimate partner violence is regularly perpetrated by partners who are also caregivers for that person, which can often prevent such violence being identified. In the DHS, intimate partner violence is considered an emotional, physical and sexual forms of violence. This study considered all three forms of violence ever perpetrated by a current or former partner. Intimate partner emotional violence was assessed using the variable addressing whether the respondent experienced any emotional violence. The variable was generated

by combining responses to whether the women had been humiliated, threatened with harm, insulted or made to feel bad by a husband or partner. **Legal capacity** refers to the right of people with disabilities to recognition everywhere as people before the law. Under international human rights law, people with disabilities have a right to legal capacity, which is distinct and independent from mental capacity, on an equal basis with individuals without disabilities. Supported decision-making mechanisms may be necessary to empower people with disabilities to exercise their right to legal capacity.

**Logistic regression** is a statistical technique that allows expressing the probability that something (e.g. experiencing violence) will happen as a linear expression of a number of explanatory variables (e.g. age, level of education, etc.). The linear expression is linked to the probability through a logistic function that can only take values between 0 and 1. The coefficients of the linear expression represent the strength of the relationship of each explanatory variable with the probability being explained. The level of significance (p-value) of each coefficient represents the probability that the estimated value of the coefficient could be due purely to chance and that its actual value is 0. Generally, one wants the p-value to be less than 0.05 or 0.01 (5 or 1 per cent), to minimize the risk of concluding that there is a relationship when there actually is not.

**Odds ratio** is the probability that something will happen divided by the probability that it will not. The results of a logistic regression are often expressed as odds ratios because this quantity is more directly linked with the format of the logistic regression equation than the probability itself.

**Person with disabilities** is the person-first language used by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to refer to a “person who has some type of physical, intellectual, mental, cognitive, or sensory impairment that in interaction with various barriers may hinder his or her full participation in society on an equal basis with others”.

**Psychological violence** refers to behaviour that is controlling, isolating, humiliating or embarrassing and which causes the person upon whom it is perpetrated psychological distress.

**Reasonable accommodation** is defined by the CRPD as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.

**Reproductive health** refers to a person’s complete physical, mental and social well-being, not only the absence of disease or illness, in all matters relating to the reproductive system and to its functions and processes. Reproductive health includes the ability to enjoy a satisfying and safe sex life and the freedom and legal capacity to decide if, when, with whom, and how often to do so. For women and young people with disabilities, this means the right to be free from forced sterilization, forced use of contraceptives and forced abortion; access to accessible information about reproductive health and safe, effective, affordable and acceptable methods of family planning; and the right to access quality

accessible maternal and newborn health services. This term and others are defined in the International Conference on Population and Development (1994).

**Reproductive rights** are human rights recognized in national laws, international laws and international human rights documents that uphold the rights of all people to decide freely and responsibly on the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. Women and young people with disabilities, as with all rights-holders, must be free to make these decisions free of discrimination, coercion or violence.

**Sexual health** is defined by the World Health Organization as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence”.

**Sexual rights** are the rights of all people to attain the highest attainable standard of sexual health free of coercion, violence and discrimination of any kind; to pursue a satisfying, safe and pleasurable sexual life; to have control over and decide freely and consensually, on matters related to their sexuality, reproduction, bodily integrity, choice and gender identity; and to accessible services, education and information necessary to do so.

**Sexual violence** refers to abusive sexual contact, making a person engage in a sexual act without consent, and attempted or completed sex acts with a person who is unable to consent to sexual contact. It can take many forms, including any unintended or non-consensual sexual act, sexual harassment and violent acts. A person may be unable to consent due to their disability (however, having a disability does not mean a person is automatically unable to consent to voluntary sexual conduct). Other reasons a person may be unable to consent include that the person is asleep, unconscious, ill, under pressure, or under the influence of drugs or alcohol.

**Supported decision-making** refers to regimes that replace substitute decision-making models, such as guardianship. Supported decision-making “comprises various support options which give primacy to a person’s will and preferences, and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.), and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.)”, as defined in the CRPD. Substituted decision-making models perpetuate power imbalances, which can make women and young people with disabilities especially vulnerable to gender-based violence and other forms of abuse and ill-treatment.

**Victim/survivor** is a person who has experienced or is currently experiencing gender-based violence. There has been debate about the use of the terms victim and survivor. The United Nations Secretary-General’s “In-Depth Study on Violence Against Women” explains that for some, “the term ‘victim’ should be avoided because it implies passivity, weakness and inherent vulnerability and fails to recognize the reality of women’s resilience



and agency. For others, the term 'survivor' is problematic because it denies the sense of victimization experienced by women who have been the target of violent crime".

**Violence against women** is defined by the United Nations as "any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life" (UN, 1993). This definition includes the many forms violence against women with disabilities can take, including intimate partner violence, caregiver violence, medical violence (e.g. forced sterilizations and other procedures, forced medication or overmedication), sexual violence, psychological violence, economic violence, institutional violence and violence during emergencies.

**Violence, non-partner** is violence committed by a caregiver (non-partner), family member, friend, acquaintance, neighbour, work colleague or stranger. Frequently, non-partner violence is committed by a person familiar to the victim/survivor. For people with disabilities, offenders can serve in a caregiver role for the person either in the person's home or in an institutional setting.

# Executive summary

Our current understanding of the relationship between disability, sexual and reproductive health and rights (SRHR) and violence against women with disabilities is limited. This report aims to examine who and where women with disabilities are, and to explore the relationships between disability and intimate partner violence (IPV) and the bodily autonomy of women of reproductive age (15–49 years). For answers, UNFPA conducted a study using Demographic and Health Surveys (DHS) data from Haiti, Mali, Pakistan, Rwanda, South Africa and Uganda, countries that applied a standard optional module on disability established by the DHS Program.

The study found that the prevalence of disability among women of reproductive age in the six countries ranges from 1 per cent in Mali to 4.4 per cent in Pakistan. Women with disabilities are more likely to be of older age, have a lower level of education, live in poverty, and be divorced than women without disabilities. There are remarkable differences across countries in the outcomes. The study found that women with disabilities are at a higher risk of experiencing violence compared with those without disabilities. The differences were less pronounced in the case of bodily autonomy. It was also found that the type of disability had a major influence on the variables studied.

The results draw attention to challenges in designing a data collection strategy for disability in the context of IPV. Currently, these two very distinct areas of data collection share a relatively small intersection in conventional data collection instruments. Based on the findings, the report makes recommendations for United Nations agencies, Member States and civil society actors, including organizations of persons with disabilities.

## Recommendations based on the findings



### Recommendation 1:

Advocate for an enabling legal, policy and social environment for autonomous decision-making.



### Recommendation 2:

Recognize the different degrees of vulnerability to IPV faced by women with different types of disability and the particular problems faced by women with cognitive/intellectual and communication disabilities.



### Recommendation 3:

Develop, advocate and implement improved research methodologies for stronger data on disability and IPV.



# Introduction

The Sustainable Development Goals (SDGs) present an ambitious agenda to transform the world by 2030. These goals are designed to eliminate poverty, discrimination, abuse and preventable deaths, address environmental destruction and usher in an era of development for all people everywhere. Disability inclusion, gender equality and addressing gender-based violence are explicitly recognized as integral to achieving this transformation.<sup>1</sup> Disability is referenced in multiple parts of the SDGs, specifically in those related to education, growth and employment, inequality, accessibility of human settlements as well as data collection and monitoring. The SDGs call for high-quality, timely and reliable data that is disaggregated by disability status, whenever possible.

Persons with disabilities are included in the SDG vision, yet they are often invisible in the data that informs decision-making in countries. This report provides data on women<sup>2</sup> with disabilities and two areas on which progress towards the SDGs depends: violence against women and bodily autonomy. There are significant limitations in our current understanding of the relationship between disability and these issues. Two data points highlight the challenge: First, persons with disabilities make up 16 per cent of the world's population,<sup>3</sup> meaning that 1 in 6 women live with a disability.<sup>4</sup> Second, across their lifetime, 1 in 3 women, around 736 million, are subjected to physical or sexual violence by an intimate partner or sexual violence from a non-partner – a number that

1 Particularly reflected in Goal 5 (Achieve gender equality and empower all women and girls), especially targets 5.1 – 5.3.

2 The report uses the gender binary according to the DHS methodology and it does not reflect UNFPA's approach to gender.

3 Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

4 WHO and World Bank (2011). World Report on Disability (Geneva: World Health Organization, 2011), pp.78, available at: [www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf). See also: WHO Fact Sheet. Disability. Available at: [www.who.int/news-room/fact-sheets/detail/disability-and-health](http://www.who.int/news-room/fact-sheets/detail/disability-and-health).

has remained largely unchanged over the past decade.<sup>5</sup> Adding to the challenge, persons with disabilities face barriers and discrimination every day and are commonly denied their rights.

This study responds to urgent calls for more accurate data to better understand IPV and the services available to survivors – and ensures such data includes women with disabilities. The analysis presented here is based on DHS data from six countries: Haiti, Mali, Pakistan, Rwanda, South Africa and Uganda. It responds to this identified gap by examining the relationships between disability and IPV exposure and bodily autonomy among women with disabilities of reproductive age (15–49 years).

This report contributes to our understanding on disability in relation to violence and particularly IPV. First, we present an overview of the existing literature and definitions together with current international normative frameworks. Then, we introduce the study objectives, methods and material. What follows is the display of the results of the analysis by focusing on IPV and bodily autonomy. Finally, we translate these findings into clear recommendations for practitioners, policymakers, United Nations entities and civil society. The recommendations chart a way forward to ensuring equality when it comes to addressing IPV for and with women with disabilities.

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5 WHO. Devastatingly pervasive: 1 in 3 women globally experience violence, available at [www.who.int/news/item/09-03-2021-devastatingly-pervasive-1-in-3-women-globally-experience-violence](https://www.who.int/news/item/09-03-2021-devastatingly-pervasive-1-in-3-women-globally-experience-violence).



# 1. Background

## International normative frameworks

Disability is increasingly understood as a human rights and development issue.<sup>6</sup> The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by consensus at the United Nations General Assembly in 2006. As of March 2024, the CRPD has been ratified by 191 out of 193 UN Member States, nearing universal ratification. Human rights related to IPV are mentioned under Article 16 (freedom from exploitation, violence and abuse); Article 6 (multiple discrimination faced by women and girls with disabilities); and Article 21 (right to information). CRPD article 11 states that all State Parties are responsible for ensuring the rights of persons with disabilities during crises.

The CRPD is aligned with the Programme of Action of the International Conference on Population and Development (ICDP) and the Beijing Platform for Action and the outcome documents of their review conferences. While the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) does not explicitly refer to women and girls with disabilities, the General Recommendation of the Committee on the Elimination of Discrimination of Women No. 18 (a) notes that women with disabilities are doubly marginalized and recognizes the scarcity of data, and (b) calls on States Parties to provide this information in their periodic reports and ensure the participation of women and girls with disabilities in all areas of social and cultural life. In addition, targets 5.2 and 5.3 of the Sustainable Development Goals call for the elimination of violence and harmful practices against all women and girls.

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<sup>6</sup> WHO and World Bank (2011). *World Report on Disability* (Geneva: World Health Organization, 2011), pp.78, available at: [www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf).

## Defining and measuring disability

Misconceptions and negative attitudes around disability are some of the leading causes of the marginalization of persons with disabilities; the same is true in research. Persons with disabilities are often excluded from national and international development efforts, policies and programmes. The term “intersecting discrimination” is used to describe the exclusion that many persons with disabilities face due to their gender, age, social and economic status, ethnicity and disability. Disability may look different and produce unique forms of disadvantage and privilege when intersecting with various identities. Disability is a complex and multidimensional phenomenon, and the variety of definitions create several challenges for measurement. Statistics on disability differ according to the definitions of disability, the data collection methods, reporting sources and the factors to be scrutinized, which can include impairments, participation restrictions, limitations of activity and environmental aspects.<sup>7</sup>

The CRPD states that persons with disabilities “include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.<sup>8</sup> In other words, disability is not the same as an impairment but emerges through the interaction of a person’s functional ability and their environment. Definitions of disability vary from one country to another, particularly definitions used to determine eligibility for programmes. In other words, disabilities are also situational and contextual.

The medical approach to disability continues to prevail as one of the most prevalent disability models despite it being broadly criticized by the disability movement, human rights advocates and disability researchers worldwide. The medical approach to disability focuses on disability as a problem of the person, directly caused by disease, trauma or other health conditions requiring sustained professional medical care/treatment, aimed at a “cure” or to the individual’s adjustment and behavioural change. Consequently, in this model, medical care and reforming health-care policies are seen as the main issues.

The human rights approach to disability sees disability as a human right and a development issue, involving the **removal of barriers** preventing full integration into society and equal participation, and the **adjustment of environments** to respond to the characteristics and needs of individuals with disabilities. Disability is not seen as an attribute of an individual, but rather a complex collection of conditions, many of which are the result of the expectations of the social environment. Hence, the management of the problem requires social intervention, and it is the collective responsibility to adapt the environment for the full participation of persons with disabilities in all areas of social life.<sup>9</sup>

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7 WHO and World Bank (2011). World Report on Disability (Geneva: World Health Organization, 2011), pp.78, available at: [www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf).

8 Convention on the Rights of Persons with Disabilities and Optional Protocol (2006). Available from: [www.un.org/disabilities/documents/convention/convoptprot-e.pdf](http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf)

9 Mitra, Sophie (2018). Disability, Health and Human Development. Springer. Available from: <https://link.springer.com/content/pdf/10.1057/978-1-137-53638-9.pdf>

In 2001, the United Nations International Seminar on the Measurement of Disability recommended that principles and standard forms for indicators of disability should be developed for use in censuses. The **International Classification of Functioning, Disability and Health**, known more commonly as ICF, is the framework endorsed by the World Health Assembly (resolution WHA 54.21) as the international standard to describe and measure health and disability. The ICF consists of an overarching framework for conceptualizing disability and a classification system for use in coding.<sup>10</sup> The ICF framework provides a mechanism for developing a harmonized approach for the collection of disability data and estimating disability prevalence. The ICF integrates the medical and the human rights-based approach to disability in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective.<sup>11</sup>

The ICF framework has been widely endorsed and represents a great achievement for data collection and measurement of disability. In addition to the ICF, the United Nations Statistical Commission adopted methodological guidelines for data collection on disability in 2015. These guidelines are to be applied in national censuses and surveys. They present recommendations and specific questions developed by the Washington Group on Disability Statistics, a team of experts from National Statistical Offices and other partners established by the UN Statistical Commission following the United Nations International Seminar on the Measurement of Disability in 2001.<sup>12,13</sup> The main purpose of the Washington Group on Disability Statistics is the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. Details of measurement are provided in the section on “Measures of explanatory variables”.

## Defining and measuring violence against women

The DHS obtains information from women aged 15–49 on their experience of violence committed by any perpetrator, including current and former spouses or other intimate partners. It also collects information on men, but this information was not used here. The DHS captures intimate partner violence for ever-married and well as never-married women. Ever-married are asked about their experience of violence committed by their current and former spouse/live-in partners and, if applicable, never-married women are asked about their experience of violence committed by their current and former intimate partners.

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10 Not to be confused with ICF International, the parent company of Macro International, the company responsible for DHS.

11 Mitra, Sophie (2006). The Capability Approach and Disability. *Journal of Disability Policy Studies* 16 (4): 236-247.

12 United Nations (2018). Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities. New York: United Nations. Available at <https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf>

13 Madans, J.H., Loeb, M.E. and Altman, B.M. (2011). Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: The Work of the Washington Group on Disability Statistics. *BMC Public Health*, 11, S4. <https://doi.org/10.1186/1471-2458-11-S4-S4>

The general definition of intimate partner violence (IPV) is behaviour within an intimate relationship that causes physical, sexual or psychological harm, including acts of physical aggression, sexual coercion, psychological abuse and controlling behaviours. This definition from the World Health Organization covers violence by both current and former spouses and partners.

## **Defining and measuring bodily autonomy**

The present analysis by UNFPA focused on several key questions in the DHS. Women's autonomy in decision-making and exercise of their reproductive rights was assessed from responses to the following three questions: "who usually makes decisions about health care for yourself?", "who usually makes the decision on whether or not you should use contraception?" and "can you say no to your husband/partner if you do not want to have sexual intercourse?" For the first two questions the response options were "respondent", "husband/partner", "respondent and husband/partner jointly" or "someone else". A woman is considered to have autonomy in reproductive health decision-making and to be empowered to exercise their reproductive rights if they: (1) decide on health care for themselves, either alone or jointly with their husbands or partners; (2) decide on use or non-use of contraception, either alone or jointly with their husbands or partners; and (3) can say no to sex with their husband/partner if they do not want to.





## 2. Objectives

### **The objectives of the study are to:**

- ▶ Synthesize the existing literature on the relationship between disability, intimate partner violence and bodily autonomy.
- ▶ Examine the relationship between disability, IPV exposure, bodily autonomy and acceptance of violence among women of reproductive age (15–49 years) using the DHS from six countries: Haiti, Mali, Pakistan, Rwanda, South Africa and Uganda.<sup>14</sup>
- ▶ Provide recommendations to improve data collection on disability, specifically concerning women of reproductive age with disabilities.

### **To this end, the study answers the following questions:**

- ▶ What is the prevalence of disability and does it vary by socioeconomic and demographic characteristics?
- ▶ What relationship exists between disability, IPV exposure, bodily autonomy and acceptance of violence among women of reproductive age (15–49 years)
- ▶ Is disability associated with distinct inequalities when it comes to exposure to IPV and bodily autonomy? Are these associations consistent across diverse countries?

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<sup>14</sup> The Demographic and Health Surveys in the six focus countries used the Washington Group questions in their questionnaires. They also offered a sample of persons with disabilities that provided significant results.



## 3. Methodology

A scoping review was carried out to explore the issues, findings and policy challenges emerging from the recent literature regarding the subject matter of the present paper. To this end, the review depended greatly on previous meta-analyses and systematic literature reviews. For the section on violence, the review focused on three meta-analyses published in 2012, 2021 and 2022. For the section on bodily autonomy, it was more difficult to find relevant literature because the concept of autonomy is relatively recent and the studies addressing issues that come under this heading for the most part do not use this terminology. Nevertheless, three meta-analyses and systematic literature reviews were identified that discussed these and related issues, published in 2017, 2021 and 2023. These were carefully scanned to identify studies that seemed relevant to the issue of bodily autonomy as defined here. To the extent possible, these studies were divided into the categories that UNFPA uses to detail the different dimensions of the subject, namely:

- ▶ Right to receive information and make decisions on body, health and sexuality, including informed consent
- ▶ Right to live a life free from violence
- ▶ Right to access sexual and reproductive health information and services
- ▶ Right to a life without discrimination

In addition to these pre-existing studies, a search was carried out on the Internet to find additional studies missed by the earlier reviews. The search criteria used for this purpose included phrases such as “disability violence”, “reproductive autonomy”, “reproductive rights disability”, “reproductive decision-making disability” and “informed consent disability”.

In the empirical part of the paper, the analysis utilizes recent data from DHS conducted since 2015 that include the Washington Group Short Set (WG-SS) of six questions on functional limitations. The DHS are nationally representative, household-based surveys of women of reproductive age (15–49 years). The study focuses on six countries: the 2016-17 Haiti DHS (N = 14,371), the 2018 Mali DHS (N = 10,519), the 2017–18 Pakistan DHS (N = 15,068), the Rwanda 2019–20 DHS (N = 14,364), the 2016 South Africa DHS (N = 8,514) and the Uganda 2016 DHS (N = 18,506). The data from the six countries was not pooled, but rather analysed separately. All analyses applied sample weights that account for sampling probability and nonresponse and `svy` commands to adjust for the clustered sampling design. All analyses were conducted in Stata SE 17.

## Measures of outcome variables

Two outcome variables were assessed from self-responses from women: IPV and bodily autonomy.

A standardized DHS module was applied in the majority of countries examined in this report. The DHS Program, in consultation with experts on the measurement of domestic violence and survey research, has developed a standard domestic violence module. It is guided by the available research on valid and reliable measurement of domestic violence and by guidelines set out by the World Health Organization (2001) on the ethical collection of such sensitive information. The part of the DHS module specific to spousal (husband or cohabiting partner) violence uses a modified version of the Conflict Tactics Scales (CTS), which includes questions that ask women whether their current or most recent (if divorced, separated, or widowed) husband/partner ever perpetrated any of a series of behaviourally-specific acts of physical or sexual violence.<sup>15</sup> Women who say yes to a particular item are then asked about the frequency of perpetration in the 12 months preceding the interview. Six different variables were constructed describing physical violence, sexual violence, and physical or sexual violence experienced during the relationship and during the 12 months prior to the survey. More specifically, IPV is measured by asking women if their current or former spouse/intimate partner ever did the following to them:



- ▶ **Sexual violence:** Physically force you to have sexual intercourse with him/her when you did not want to; physically force you to perform any other sexual acts you did not want to; force you with threats or in any other way to perform sexual acts you did not want to.
- ▶ **Physical violence:** Push you, shake you or throw something at you; slap you; twist your arm or pull your hair; punch you with a fist or with something that could hurt you; kick you, drag you or beat you up; choke you or burn you

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15 Straus, M.A. (1979). Measuring Intra-Family Conflict and Violence - Conflict Tactics (CT) Scales. *Journal of Marriage and Family* 41(1):75-88.

on purpose; or attack you with a knife, gun or other weapon. Physical violence is further divided into moderate and severe violence. The former includes pushing, shoving and slapping. The latter refers to kicking, hitting with the fist or an object, being beaten up, and threats with a knife or other weapon.

▶ **Psychological/emotional violence:** Say or do something to humiliate you in front of others; threaten to hurt or harm you or someone you care about; insult you or make you feel bad about yourself.

In addition to the questions on different forms of intimate partner violence, the DHS also obtains information about physical violence committed by anyone other than any spouse/intimate partner since they were age 15 by asking if anyone has hit, slapped, kicked or done something else to hurt them physically. All women were also asked if they had experienced sexual violence committed by anyone other than any spouse/intimate partner. They are asked if at any time in their life, as a child or as an adult, they were forced in any way to have sexual intercourse or to perform any other sexual acts when they did not want to. This information, however, was not used in the present study, which is limited to IPV.

A woman was considered as having experienced IPV if she reported that she had experienced any one of the following: sexual violence, emotional violence or physical violence from a current or former intimate partner.

Finally, a question was asked about the **acceptance of violence**, namely agreement to the statement that a husband is justified in hitting or beating his wife for specific reasons, such as the following:

- ▶ Goes out without telling him
- ▶ Neglects the children
- ▶ Argues with him
- ▶ Refuses to have sexual intercourse with him
- ▶ Burns the food
- ▶ Refuses to cook
- ▶ Comes home late
- ▶ Is unfaithful to him

For the purposes of this study acceptance was defined as acceptance of at least one of these reasons as a valid motive for wife beating.

## Measures of explanatory variables

The main explanatory variable of interest is the disability status of the woman. Our research on disability is made possible as the DHS Program established a standard optional module

on disability<sup>16</sup>, as the collaborative result of the United States Agency for International Development and the Washington Group on Disability Statistics. The standard module adapted its questions from the WG–SS on functional limitations.<sup>17</sup> The respondent to the household questionnaire provides information on all de facto household members aged 5 and above. The module covers six functional areas: vision, hearing, communication, cognition (remembering and concentrating), mobility (walking or climbing steps) and self-care (washing all over and dressing). Each person’s level of difficulty in each domain is categorized on a 4-point scale: no difficulty, some difficulty, a lot of difficulty, or cannot perform task/function at all. Annex II shows an excerpt of how these questions are asked in the DHS questionnaire.

Using the cutoff recommended by the Washington Group for analysis of the WG–SS, we limited the target population to those experiencing a lot of difficulty in performing a given function or who cannot perform it at all, rather than on all persons experiencing some degree of difficulty.<sup>18</sup> Based on this, we derived a dichotomous measure of the presence of any disability (that is, a lot of difficulty or cannot perform the function at all) in at least one of the six functional areas.

The approach, as noted above, was to analyse data on disability and examine bodily autonomy and IPV exposure of persons with disabilities by providing quantitative evidence using data on disability collected from the DHS in six countries (Haiti, Mali, Pakistan, Rwanda, South Africa and Uganda) that have applied the DHS survey with the new format using the WG–SS.

**Figure 1: The six countries of this study**



*\* The designations employed and the presentation of the material on the map do not imply the expression of any opinion whatsoever on the part of UNFPA concerning the legal status of any country, territory, city or area or its authorities, or concerning the delimitation of its frontiers or boundaries.*

16 ICF International (2016). Demographic and Health Surveys Disability Module, Demographic and Health Surveys Methodology. Rockville, MD: ICF International.

17 Washington Group on Disability Statistics (2020b). The Washington Group Short Set on Functioning (WG-SS). Hyattsville, MD: Washington Group on Disability Statistics.

18 Washington Group on Disability Statistics (2020). Analytic Guidelines: Creating Disability Identifiers Using the Washington Group Short Set on Functioning (WG-SS) Stata Syntax. Hyattsville, MD: Washington Group on Disability Statistics.

## Data analysis methods

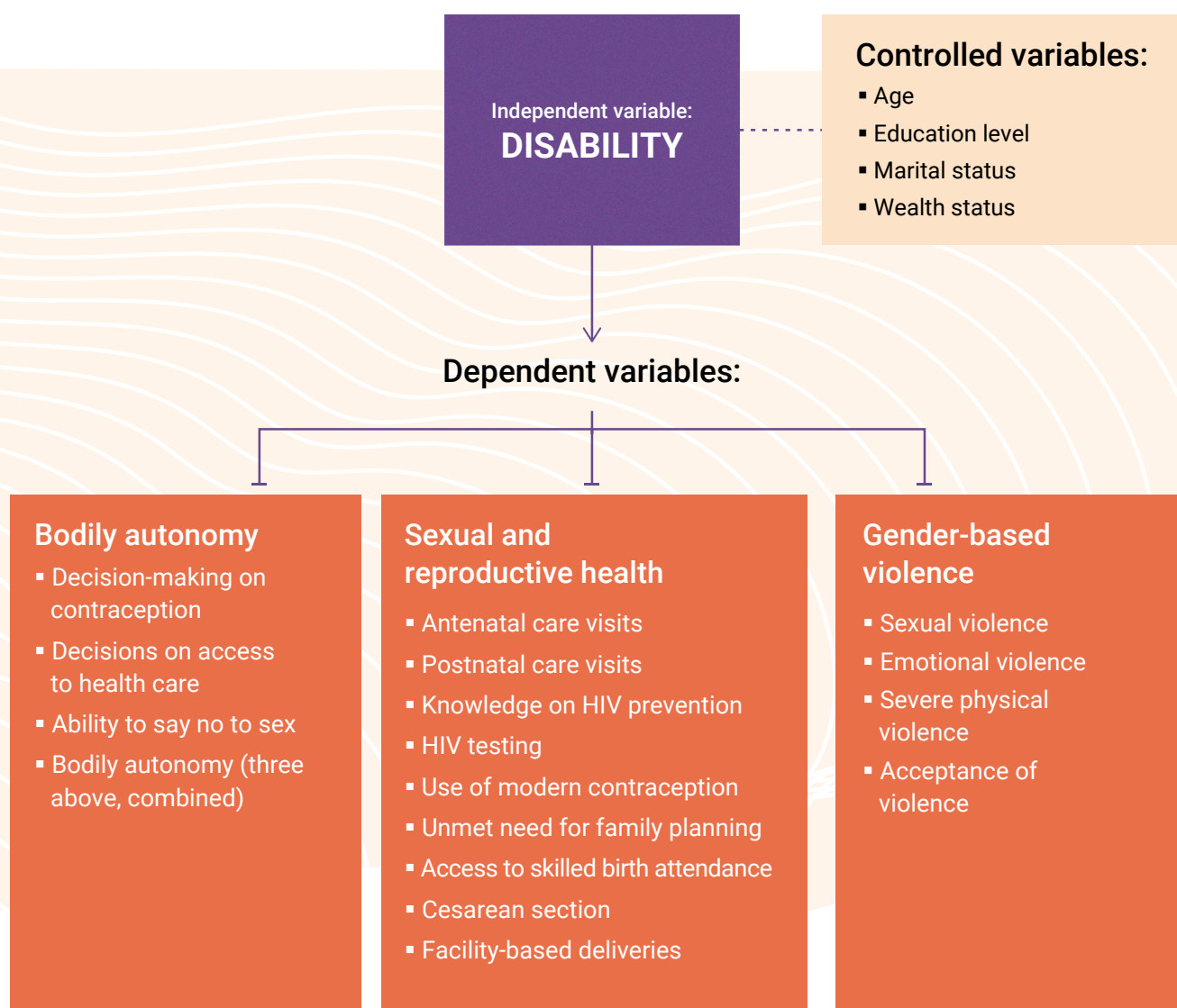
The overall research question for this analysis is to examine what relationship exists between disability and IPV exposure among women of reproductive age (15–49 years), as stated in the objectives. The analysis aims to answer the following specific questions:



- ▶ What are the main issues and policy challenges that emerge out of the existing literature on the relation between disability, IPV and bodily autonomy?
- ▶ What is the prevalence of disability, and does it vary by socioeconomic and demographic characteristics?
- ▶ Is disability associated with distinct inequalities when it comes to exposure to IPV and bodily autonomy?
- ▶ Are these associations consistent across diverse countries?

Descriptive analysis was used to describe the sample and assess the relationship between disability and the various outcomes. We also estimate a parsimonious logistic regression model with a basic set of sociodemographic characteristics as control variables to isolate the effect of disability status on selected outcomes. Figure 2 illustrates the variables used in the analysis. In the regression models, control variables were age, education level, marital status and wealth status. In addition, the multivariate analysis at the end of this report differentiates between types of disability and urban/rural residence. The rest of the report will focus mainly on bivariate results, without controlling for these co-variables. We notice that most of the results are not statistically significant. The major reason for that is that the number of persons with disabilities included in sample sizes used in the DHS for the study countries is small, resulting in limited power to detect differences. The interpretation of results will focus on the size and direction of the relationships between the outcome variables and disability, either directly or controlling other relevant determining factors.

**Figure 2: Variables used in the study**



## Limitations of the study

The sampling of DHS surveys is not specifically oriented towards the investigation of disability and as a result, as noted, the number of persons with disabilities that are included in the samples in surveys of this kind is typically small. This limits the power to detect differences and the number of control variables that can be included. In the current study, this limitation is circumvented to some extent by pooling the data of various countries and including the specific country concerned as a control variable. However, even with this design it is not possible to include factors such as ethnicity, income, sexual orientation and age difference between the partners or others that might be additional relevant determinants of exposure to violence, either because the DHS does not ask these questions or because the sample sizes do not allow for including too many variables.

As mentioned in the methodology section, the DHS disability module is part of the household questionnaire, which means that it is not necessarily answered by the person him or herself. This is probably inevitable in the case of persons with severe intellectual disabilities (ID); however, the perception of the person affected may not be the same as that of other household members.

Another problem is the limited number of questions about disability. The DHS does not allow, for example, to know since when a person has a given disability. More specifically, it is not possible to know if the person already had the disability at the time when the reported violent action occurred. This may lead to over-estimation of the effect of disability on violence in older women. The cause of the disability is also not known, i.e. whether it is the result of a birth defect, ageing or an accident.

Underlying power structures such as ableism, and the experience of stigma and discrimination, also internalized stigma, may play an important role in the social ecology of IPV and bodily autonomy. This may result in censorship and underreporting of certain issues by the survey respondents.







## 4. Existing studies and meta-analyses

### 4.1 Existing studies and meta-analyses on the relation between disability, IPV and other forms of violence and bodily autonomy

A recent study carried out by Kerry et al. using the ICF framework analysed the relationship between disability and different components of reproductive health among women of reproductive age, based on the same six countries used in this report, plus three others (Nigeria, Senegal and Timor-Leste).<sup>19</sup> In their conclusions, the authors state:

*In contrast to our expectation, we did not find widespread disadvantage in health care access and health outcomes for women with disability. Rather, we found that women with disabilities are similar to women without disabilities in terms of their fertility intentions, sexual activity, and use of maternal health services. Encouragingly, we find that women with disabilities have similar or higher rates of contraceptive knowledge and use and are consistently less likely to experience unintended pregnancy. Of concern, we find that women with disabilities experience greater difficulties accessing medical services when sick in almost half of our study countries.*

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<sup>19</sup> Kerry L.; D. MacQuarrie and Julia Fleuret (2022). Patterns of Reproductive Health among Women with Disabilities. ICF, Rockville MD, DHS Analytical Studies No. 80.

There may be reasons related to the way that disability is measured in the DHS that account for this apparent lack of association, which are addressed in the Methodology section. Nevertheless, the existence of this previous study, which is largely based on the same data sources, was the motivation for focusing the present study on two issues that it did not cover, namely IPV and bodily autonomy.

Recent studies are finding that both adult women and men<sup>20</sup> with disabilities experience a higher incidence of different types of violence, a finding that has been replicated in an increasing number of studies. Most of these studies are from more developed countries, particularly Australia, Canada, the United Kingdom and the United States. The number of studies based on developing countries is slow but growing.

In addition to the growing number of specific studies, several major meta-analyses compare the findings of these studies and draw some general conclusions. The advantage of meta-analyses is that they summarize the results of a large number of individual studies, thereby minimizing the chance of atypical results deriving from the particularities of specific studies. Pooling data from different studies also helps to overcome the lack of significance of the results of each individual study. However, meta-analyses need to resolve the challenge of comparing studies with disparate designs. Some focus on women while others mix men and women, some focus only on sexual violence while others consider a wider range of violence, some focus on particular kinds of disabilities while others consider all kinds. There may be differences in the definitions of adulthood, for example, and individual studies may use different types of data, such as institutional data versus population-based surveys.

### **Meta-analyses of the relationship between disability and victimhood**

The oldest review included in the present study, from 2001 by Curry et al., was generally skeptical about the relationship between disability and sexual violence, but only considered a small number of individual studies.<sup>21</sup> A second, published in 2012 by Hughes et al. in *The Lancet*, compared 26 articles on different types of violence published between 1990 and 2010.<sup>22</sup> Unlike the other analyses, this one considered not only sexual violence, but also other types of violence. Only 12 of the 26 studies included measured violence in individuals with and without disabilities. Only one study was from a developing country, namely South Africa,<sup>23</sup> plus two studies from Taiwan,<sup>24,25</sup> none of which allowed the direct comparison of persons with and without disabilities.

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20 There are also several studies about disability and violence in children, but these will not be discussed here.

21 Curry, M. A.; D. Hassouneh-Phillips and A. Johnston-Silverberg (2001). Abuse of women with disabilities: An ecological model and review. *Violence Against Women*, 7 (1): 60–79.

22 Hughes, K.; M. Bellis; L. Jones; S. Wood; G. Bates; L. Eckley et al. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet* 379 (926): 1621-9.

23 Carlile, J. B. (1991). Spouse assault on mentally disordered wives. *Can J Psychiat* 36 (4): 265-9.

24 Hsu, C. C.; C. J. Sheu; S. I. Liu, Y. W. Sun, S. I. Wu and Y. Lin (2009). Crime victimization of persons with severe mental illness in Taiwan. *Aus N Z J Psychiatry* 43 (5): 460-6.

25 Lin, L. P.; C. F. Yen; F. Y. Kuo; J. L. Wu and J. D. Lin (2009). Sexual assault of people with disabilities: Results of a 2002-2007 national report in Taiwan. *Res Dev Disabil* 2009; 30(5): 969-75.

In 2021, Tomsa et al. published a meta-analysis in the *International Journal of Environmental Research and Public Health* based on 25 country studies, including two from South Africa, one from Sri Lanka and two from Taiwan. It focused on sexual abuse in adults with intellectual disability. Another meta-analysis on sexual violence was published in 2022 by Amborski et al. in the Journal *Trauma, Violence and Abuse*.<sup>26</sup> It compared the findings of 68 studies published between 1988 and 2018, including four studies based on data from developing countries, plus a study from Taiwan. There is some overlap between the meta-analyses by Hughes et al. (2012), Tomsa et al. (2021) and Amborski et al. (2022). Between all three, they reviewed six studies from four developing countries plus four studies from Taiwan.<sup>27,28,29,30,31,32</sup>

### Meta-analysis by Hughes, et al., in *The Lancet* (2012)

This meta-analysis found that the pooled crude odds ratios for the risk of recent (last 12 months) violence in individuals with disabilities compared with individuals without disabilities were 1.50 for all studies combined, 1.31 for persons with non-specific impairments, 1.60 for persons with intellectual impairments, and 3.86 for those with mental illnesses.<sup>33</sup> These figures include the 12 studies that measured violence in individuals with and without disabilities as well as the studies that included only persons with disabilities. The odds ratios were slightly higher for intimate partner violence (1.78) than for physical violence (1.35) and slightly higher for mixed-sex studies (1.69) than for studies focused on women only (1.39). However, due to the relatively small number of studies considered and the small sample sizes of most of the individual studies, few of the effects reached the level of statistical significance.

Of the studies included in the analysis, 19 reported findings for mixed-sex samples, whereas seven included women only. The analysis did not provide details on the levels and types of violence experienced by men and women, aside from the difference in odds ratios noted above. It noted, however, that small-scale studies from low-income and

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26 Amborski, Amylee Mailhot; Eve-Line Bussi eres; Marie-Pier Vaillancourt-Morel and Christian C. Joyal (2022). Sexual violence against persons with disabilities: a meta-analysis. *Trauma, Violence and Abuse* Vol. 23 (4): 1330–1343.

27 Carlile, J. B. (1991). Spouse assault on mentally disordered wives. *Can J Psychiat* 36 (4): 265-9.

28 Dickman, B. J. and A. J. Roux (2005). Complainants with learning disabilities in sexual abuse cases: A 10-year review of a psycholegal project in Cape Town, South Africa. *British Journal of Learning Disabilities*, 33(3), 138–144.

29 Opoku, M. P.; N. Huyser, N.; W. K. Mprah; B. A. Alupo and E. Badu. (2016). Sexual violence against women with disabilities in Ghana: Accounts of women with disabilities from Ashanti Region. *Disability, CBR & Inclusive Development*, 27(2): 91–111.

30 Puri, M.; G. Misra and S. Hawkes (2015). Hidden voices: Prevalence and risk factors for violence against women with disabilities in Nepal. *BMC Public Health*, 15 (1): 261.

31 Shabalala, N. and A. Jasson (2011). PTSD symptoms in intellectually disabled victims of sexual assault. *South Afr. J. Psychol.* 41: 424–436.

32 Vadasinghe, A. N.; P. B. Dassanayaka; M. Sivasubramaniam; D. P. P. Senasinghe; A. N. Samaranyake and W. M. M. P. H. Wickramasinghe (2017). A study on sexual violence inflicted on individuals with intellectual developmental disorder. *Disability and Health Journal*, 10 (3): 451–454.

33 The odds ratio is a statistical concept that expresses the ratio between the probability that something will be the case divided by the probability that it will not. If the probability that something will be the case or not is evenly divided, at 50% each, the odds ratio is 1. In statistical models of multivariate analysis, particularly logistic regression, it is often more convenient to work with the odds ratios, rather than the probabilities themselves.

middle-income countries, such as those for the Indian state of Orissa and for Uganda,<sup>34,35</sup> were not included in the analysis because they did not meet the selection criteria, yet these small-scale studies emphasize the vulnerability of persons with disabilities to violence, particularly women.

### **Meta-analysis by Tomsa et al. (2021)**

The meta-analysis carried out by Tomsa et al. was limited to estimating the prevalence of violence against persons with disabilities and did not make comparisons with persons without disabilities.<sup>36</sup> The combined prevalence of sexual abuse in adults with intellectual disability (ID) was 32.9 per cent. Overall, the United Kingdom had the highest prevalence (34.1 per cent) and the United States had the lowest (15.2 per cent). The overall prevalence in females was lower (31.8 per cent) than that in males (39.9 per cent). Subgroup analyses revealed that prevalence of sexual abuse was higher in institutionalized individuals. The most prevalent profile of abuser is of a peer with ID. Prevalence increases from mild to severe levels of ID and decreases in profound levels of ID. It is also more prevalent when the informant is an individual with an ID than when someone else reports abuse.

### **Meta-analysis by Amborski et al. (2022)**

The meta-analysis on sexual violence by Amborski et al. considered a larger number of studies, some of which with large sample sizes.<sup>37</sup>

The meta-analysis concluded that reported sexual violence based on retrospective data is significantly higher for both men and women with disabilities. The average odds ratio for the 68 studies combined was 2.27. There were, however, significant variations depending on the country, the type of disability and the design of the study. Considering only the largest studies included in the sample, Smith found an odds ratio of 2.38 in a behavioural risk factor surveillance system in the United States,<sup>38</sup> Mitra and Mouradian found an odds ratio of 2.7 based on other United States data,<sup>39</sup> and Krnjacki et al. found an odds ratio of 2.31 in Australia.<sup>40</sup> In contrast, Khalifeh et al. reported an odds ratios

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34 Mohapatra S. and M. Mohanty (2005). Abuse and activity limitation: a study on domestic violence against disabled women in Orissa, India. Orissa: Swabhiman.

35 Human Rights Watch (2010). "As if we weren't human": discrimination and violence against women with disabilities in Northern Uganda. New York, Human Rights Watch.

36 Tomsa, Raluca; Smaranda Gutu; Daniel Cojocar; Belén Gutiérrez-Bermejo; Noelia Flores and Cristina Jenaro (2011). Prevalence of Sexual Abuse in Adults with Intellectual Disability: Systematic Review and Meta-Analysis. *Int. J. Environ. Res. Public Health* 18, 1980.

37 Amborski, Amylee Mailhot; Eve-Line Bussi eres; Marie-Pier Vaillancourt-Morel and Christian C. Joyal (2022). Sexual violence against persons with disabilities: a meta-analysis. *Trauma, Violence and Abuse* Vol. 23 (4): 1330–1343.

38 Smith, D. L. (2008). Disability, gender and intimate partner violence: Relationships from the behavioral risk factor surveillance system. *Sexuality and Disability*, 26: 15–28.

39 Mitra, M. and V. E. Mouradian (2014). Intimate partner violence in the relationships of men with disabilities in the United States: Relative prevalence and health correlates. *Journal of Interpersonal Violence*, 29 (17): 3150–3166.

40 Krnjacki, Lauren; Eric Emerson; Gwynnyth Llewellyn and Anne M. Kavanagh (2012). Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study. *Australian and New Zealand Journal of Public Health* 2016 vol. 40 no. 1: 16-21.



of only 1.08 for the United Kingdom.<sup>41</sup> Other studies did not find significant differences between persons with or without disabilities.<sup>42,43,44</sup> This is mostly because they focused on specific population sub-groups such as younger women.

The analysis quantified the effect of several control variables (which the authors call moderating factors), with the following conclusions: The strength of the relationship of reported violence with sexual violence increases with age, being much stronger for persons over age 21 than for younger persons. The type of disability has a major effect on the results, with odds ratios of 7.57 for sensory and 5.79 for language disabilities, whereas physical disabilities and disabilities of intellectual development are associated with lower odds ratios, of 1.71 and 1.81 respectively. There is significant regional variation, with very high odds ratios in Africa (20.02) and, to a lesser extent, Australia (3.84), whereas odds ratios in Western Europe were found to be significantly lower (1.60). These results must be interpreted with caution, however, as the analysis contained only two studies from African countries.

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41 Khalifeh H.; L. Howard L.; D. Osborn; P. Moran and S. Johnson (2013). Violence against people with disability in England and Wales: Findings from a national cross-sectional survey. *PLoS One* 8(2):e55952.

42 Haydon, A. A.; A. L. McRee and C. Tucker Halpern (2011). Unwanted sex among young adults in the United States: The role of physical disability and cognitive performance. *Journal of Interpersonal Violence*, 26(17), 3476–3493.

43 Mueller-Johnson, K.; M. P. Eisner and I. Obsuth (2014). Sexual victimization of youth with a physical disability: An examination of prevalence rates, and risk and protective factors. *Journal of Interpersonal Violence*, 29 (17): 3180–3206.

44 Young, M. E.; M. A. Nosek; G.; Howland; G. Chanpong, G. and D. H. Rintala (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 78: S34–S38.

## 4.2 Gender aspects within the research limitations

A wide variety of studies are included within the meta-analyses reviewed by UNFPA for the present research report, which contributes to some limitations. Perhaps most importantly, there was a lack of data to assess the effects of gender and relationship with the sexual offenders. The lack of information in many of the primary studies also meant that it was not possible to study the potential moderating role of sexual and gender diversity on sexual victimization. Although the aim was to examine the moderator role of type of abuse (with or without physical contact) and relationship with the perpetrator, this information was not systematically reported in the studies reviewed. The type of housing (e.g. private house versus institutional; living independently versus with daily support) might also represent a significant moderating factor in the link between disability and sexual victimization.

None of the meta-analyses discussed above provide very detailed information on differentials by sex. However, the studies do provide some details. For example, Krnjacki et al. (2016) found that women with disabilities are at the greatest risk of sexual and intimate partner violence. Similar findings were also reported by several other studies.<sup>45,46,47,48</sup> Specifically, other authors reported that the pattern of gender difference in the experience of violence was similar to that found among men and women without disabilities, i.e. men are more likely than women with disabilities to experience physical violence, while women are more likely to experience sexual violence, partner violence and stalking and harassment.<sup>49,50</sup>

Studies on sexual violence against men with disabilities are relatively rare and those that exist are usually careful to make a comparison with the prevalence of similar forms of violence against women.<sup>51,52,53,54,55</sup> The consensus seems to be that both among men and women, there is a considerable difference between the prevalence of sexual violence against persons with or without disabilities, but that sexual violence against

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- 45 Hahn, J. W.; M. C. McCormick; J. G. Silverman; E. B. Robinson and K. C. Koenen (2014). Examining the impact of disability status on intimate partner violence victimization in a population sample. *J Interpers Violence* 29 (17): 3063-85.
- 46 Mitra, M.; V. E. Mouradian and M. Diamond (2011). Sexual violence victimization against men with disabilities. *American Journal of Preventive Medicine* 41(5): 494–497.
- 47 Astbury, J. and F. Walji (2014). The prevalence and psychological costs of household violence by family members against women with disabilities in Cambodia. *Interpers Violence* 29:3127-49.
- 48 Hughes, R. B.; E. Lund; J. Gabrielli; L. Powers and M. A. Curry (2011). Prevalence of interpersonal violence against community-living adults with disabilities: A literature review. *Rehabil Psychol.* 56 (4): 302-19.
- 49 Goodman, L.; M. Salyers; K. Mueser; S. Rosenberg; M. Swartz; S. M. Essock SM, et al. (2001). Recent victimization in women and men with severe mental illness: Prevalence and correlates. *J Trauma Stress* 14 (4): 615-32.
- 50 Khalifeh H.; L. Howard L.; D. Osborn; P. Moran and S. Johnson (2013). Violence against people with disability in England and Wales: Findings from a national cross-sectional survey. *PLoS One* 8(2):e55952.
- 51 Mitra, M.; V. E. Mouradian and M. Diamond (2011). Sexual violence victimization against men with disabilities. *American Journal of Preventive Medicine* 41(5): 494–497.
- 52 Mitra, M.; V. E. Mouradian and M. Diamond (2011). Sexual violence victimization against men with disabilities. *American Journal of Preventive Medicine* 41(5): 494–497.
- 53 Mitra, M. and V. E. Mouradian (2014). Intimate partner violence in the relationships of men with disabilities in the United States: Relative prevalence and health correlates. *Journal of Interpersonal Violence*, 29 (17): 3150–3166.
- 54 Mitra, M.; V. E. Mouradian; M. H. Fox and C. Pratt (2016). Prevalence and characteristics of sexual violence against men with disabilities. *American Journal of Preventive Medicine* 50(3): 311–317.
- 55 Powers, L. E.; M. A. Curry; E. McNeff; M. Saxton; J. L. Powers and M. Oswald (2008). End the silence: A survey of abuse against men with disabilities. *Journal of Rehabilitation*, 74(4): 41.

women with disabilities is considerably higher than against men with disabilities. Mitra et al. also note that, while sexual violence against women with disabilities is perpetrated almost exclusively by men, 58 per cent of sexual violence against men with disabilities is perpetrated by women, whereas 42 per cent is perpetrated by other men.<sup>56</sup>

Studies that focus on physical sexual violence against women are much more common and there is even a meta-analysis specifically dedicated to this subject.<sup>57</sup> Unfortunately, this analysis is limited to studies carried out in the United States. It analysed the results of 24 such studies, carried out between 1997 and 2009 and noted that there is general agreement on the fact that women with disabilities suffer greater prevalence of physical and sexual violence than women without disabilities. The size of this difference, however, varied considerably between studies. A study by Young et al. in 1997 compared rates of lifetime prevalence of emotional, physical and sexual abuse of women with disabilities to women without disabilities. It found that that 62 per cent of both groups had experienced such abuse. The proportion of women with disabilities to women without disabilities who reported emotional abuse was 51.7 versus 47.5 per cent, for physical abuse 35.5 versus 35.6 per cent, and for sexual abuse 39.9 versus 37.1 per cent. Other authors have reported much greater differences. For example, Martin et al. found that women with disabilities experienced similar rates of physical abuse and were 4 times more likely to have experienced a sexual assault.<sup>58</sup> In a study of 1,152 women interviewed at family practice clinics, women who reported experiencing some type of abuse (physical, sexual and emotional) in their current relationships were more than twice as likely to report having a disability.<sup>59</sup>

Our review of numerous studies finds that women with disabilities are exposed to multiple potential abusers, including intimate partners, family members, health-care providers and personal assistance service workers. The most commonly identified perpetrators of abuse against this population are husbands, live-in partners, and men, yet abuse by personal assistance providers remains a significant issue due to its prevalence and impact.<sup>60,61,62</sup>

The present analysis notes that more work needs to be done in identifying risk factors for exposure to violence. As of the date of this UNFPA study, the only risk factors that have been identified quantitatively include unemployment,<sup>63</sup> isolation, age, education and

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56 Mitra, M.; V. E. Mouradian; M. H. Fox and C. Pratt (2016). Prevalence and characteristics of sexual violence against men with disabilities. *American Journal of Preventive Medicine* 50(3): 311–317.

57 Plummer, S.-B., and P. A. Findley (2012). Women with disabilities' experience with physical and sexual abuse: A review of the literature and implications for the field. *Trauma, Violence & Abuse*, 13(1): 15–29.

58 Martin, S. L.; N. Ray; D. Sotres-Alvarez; L. L. Kupper; K. E. Moracco; P. A. Dickens; P. Scandlin and Z. Gizlice (2006). Physical and sexual assault of women with disabilities. *Violence Against Women* 12: 823-837.

59 Coker, A. L.; P. H. Smith and M. K. (2005). Intimate partner violence and disabilities among women attending family practice clinics. *Journal of Women's Health*, 14: 829-838.

60 McFarlane, J.; R. B. Hughes; M. A. Nosek; J. Y. Groff, N. Swedlend and P. D. Mullen, P. D. (2001). Abuse assessment screen disability (AAS-D): Measuring frequency, type, and perpetrator of abuse toward women with physical disabilities. *Journal of Women's Health & Gender-Based Medicine* 10: 861-866.

61 Milberger, S.; N. Israel and B. LeRoy (2003). Violence against women with physical disabilities. *Violence and Victims* 18: 581-591.

62 Saxton, M.; M. A. Curry; L. E. Powers; S. Maley; K. Eckels and J. Gross (2001). "Bring my scooter so I can leave you": A study of disabled women handling abuse by personal assistance providers. *Violence Against Women* 7: 393-417.

63 Smith, D. L. and D. R. Strauser (2008). Examining the impact of physical and sexual abuse on the employment of women with disabilities in the United States: An exploratory analysis. *Disability & Rehabilitation* 30: 1039-1046.

mobility. Nosek et al. found individuals who are younger, more highly educated, and less mobile were at a higher risk of abuse.<sup>64</sup>

### 4.3 The state of knowledge on disability and experience of violence

As is clear from the above, the number of studies on violence against persons with disabilities has grown considerably over the past two decades and some facts now seem firmly established: not only that persons with disabilities face a much higher prevalence of different kinds of violence, but also that this prevalence varies considerably according to the type of disability. However, despite the increased knowledge on the subject, there are still several areas where more research is warranted.

The increase in the number of studies on the subject has occurred in a handful of high-income countries and knowledge on the situation in less-developed countries continues to be very limited. This is particularly true of studies derived from large population-based surveys. Almost all work that has been done on the subject in developing countries is based on small samples, often referring to very specific population groups. The official government agencies responsible for data collection on violence often do not publish them according to the criteria that would allow detailed analysis.

The United Nation's Committee of Independent Experts on the Rights of Persons with Disabilities (CRPD) recently criticized the crime records of several countries for the lack of separate data on cases of gender-based violence against women and girls with disabilities and intimate partner violence. The CRPD recommends that data should be collected by sex, age, place of residence, relationship with perpetrator and disability in cases of violence and exploitation, including gender-based violence against women and girls with disabilities, and violence inflicted by intimate partners.

The present study is based on relatively large population-based samples from developing countries, albeit samples that were not designed with this particular application in mind.

There is considerable evidence that the pattern observed among the general population, of greater physical violence against men and a higher prevalence of sexual and partner violence against women, also applies to victims with disabilities. However, the degree to which disability increases these risks in men and women has not been as well researched.

Significantly, there is still a considerable lack of understanding with respect to the social and economic factors that co-determine the higher prevalence of different types of violence against persons with disabilities. Persons with disabilities typically occupy more vulnerable positions in society, are more likely to be poor or unemployed and generally have less autonomy than persons without disabilities. There is uncertainty about the degree to which these more general social and economic disadvantages, including the differences

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<sup>64</sup> Nosek, M. A.; R. B. Hughes; H. B. Taylor and P. Taylor (2006). Disability, psychosocial, and demographic characteristics of abused women with physical disabilities. *Violence Against Women* 12: 838-850.



between countries according to their level of development, are responsible for the observed differences in the prevalence of violence between persons with or without disabilities.<sup>65,66</sup>

## 4.4 Bodily autonomy in scientific literature

The bodily autonomy of women and girls refers to the right of a woman or girl to make autonomous decisions about her own body and reproductive functions, without violence or coercion. The scientific literature regarding the bodily autonomy of women with disabilities is more fragmented than the literature on violence against persons with disabilities. The concept of bodily autonomy is a relatively recent one and few studies address it in a comprehensive manner. Rather, most of them focus on specific aspects of the question and on specific disabilities, especially intellectual disabilities (ID). As a result, the study of what has now become known as bodily autonomy is disproportionately focused on some specific issues such as:



- ▶ **Forced sterilization of persons with disabilities:** This subject has been particularly controversial because it is inextricably linked to traumatic historical contexts such as the eugenics movement, based on ableist and racist ideologies about who should be allowed to have children. Because bodily autonomy is, at least in part, a rights issue, much of the literature has a legal focus, to assess or criticize the barriers posed by existing legislation in particular contexts, especially in countries such as Australia or the United States.
- ▶ **Studies on intellectual disabilities:** Intellectual disabilities are heavily over-represented in studies, in particular the challenges of decision-making in persons with intellectual disabilities. While in the case of other disabilities there is, in principle, no reason why the decision-making power of the persons affected should be curtailed in any way, the ethics of delegated decision-making in the case of serious intellectual disabilities is more problematic. Some are truly unable to take their own health-care decisions and depend on “substitute decision-making” by their guardians. In other cases, decisions can only be made with significant outside help.
- ▶ **Focus on the perceptions of guardians and medical professionals:** Until recently, data on the perceptions of persons with disabilities themselves was limited, which is why a large part of the existing research focuses on the opinions and perceptions of those who care for these persons, particularly in the case of ID. The present study takes a different view in that it assesses the opinion of the persons with disabilities about the degree to which they feel that different aspects of their bodily autonomy are being respected. This opens up a new line of inquiry that has thus far not been very common in the literature.

65 Mikton C. and T. Shakespeare (2014). Introduction to special issue on violence against people with disability. *J Interpers Violence* 29 (17): 3055-62.

66 Perry, B. (2001). *In the Name of Hate*. New York (NY), Routledge.

In addition to these biases, the existing literature sometimes tends to touch on questions of bodily autonomy in the context of other issues, such as the knowledge of persons with disabilities regarding SRH issues and quality of SRH care received by persons with disability. Many studies address both of these issues simultaneously, in ways that make it difficult to draw a clear distinction between reproductive care and reproductive autonomy. For example, a very comprehensive meta-analysis of the issues involved in the sexual and reproductive rights of persons with intellectual disabilities was recently carried out by Pérez-Curiel et al.<sup>67</sup> They systematically reviewed the current qualitative and quantitative evidence in regard to Articles 23 (right to home and family) and 25 (health, specifically sexual and reproductive health) of the Convention on the Rights of Persons with Disabilities (CRPD), with a total of 151 articles, categorized into six themes: attitudes, intimate relationships, sexual and reproductive health, sexuality and sex education, pregnancy and parenthood. The present literature review draws extensively on this meta-analysis. However, it includes many articles that deal with the knowledge and capacity of persons with intellectual disabilities to take decisions and the quality of SRH care, rather than with bodily autonomy per se.

Similarly, an earlier meta-analysis prepared by Carter et al. does not specifically address bodily autonomy. The meta-analysis reviewed 68 studies in English-speaking, high-income countries published between 2000 and 2019 in five domains: (1) sexual development including sexual desire, identities, relationships and menstruation; (2) sexual knowledge including sexuality education and sexual self-advocacy; (3) sexual activity and contraceptive use; (4) access to HPV immunization and cervical cancer screening; and (5) pregnancy, childbirth and parenthood.<sup>68</sup> The strongest factors in enabling agency were social support and sexuality education. Carter et al. found that several barriers including paternalist attitudes and infantilization of young people with intellectual disability affected all aspects of sexual expression, leading to the persistence of unfair and avoidable health inequities over the past two decades. An even larger meta-analysis of 226 studies was carried out in 2017 by Braathen, Rohleder and Azalde, but this study too has a broader focus. Slightly more than half of the studies focus on intellectual, developmental or behavioural disabilities, and it does not refer explicitly to “bodily autonomy”.<sup>69</sup>

The following discussion selected the most relevant studies from these three meta-analyses by Pérez-Curiel et al., Carter et al. and Braathen, Rohleder and Azalde, in addition to some studies found elsewhere. For the most part, this discussion will follow the thematic sub-divisions currently used by UNFPA.<sup>70</sup>

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67 Pérez-Curiel, Patricia; Eva Vicente; Lucía Morán and Laura E Gómez (2023). The Right to Sexuality, Reproductive Health, and Found a Family for People with Intellectual Disability: A Systematic Review 3Int J Environ Res Public Health 20 (2): 1587.

68 Carter, A.; I. Strnadová, C. Watfern; P. Pebdani; D. Bateson; J. Loblinzk; R. Guy and C. Newman (2021). The sexual and reproductive health and rights of young people with intellectual disability: A scoping review. Sex. Res. Soc. Policy 19: 372-390.

69 Braathen, Stine H.; Poul Rohleder and Gloria Azalde (2017). Sexual and reproductive health and rights of girls with disabilities. A review of the literature. Oslo, SINTEF.

70 UNFPA (2022). Advocacy brief: Disability and the Right to Bodily Autonomy. Available at <https://www.unfpa.org/resources/advocacy-brief-disability-and-right-bodily-autonomy>.



#### **4.5 Right to receive information and make decisions on body, health and sexuality, including informed consent**

One of the most problematic aspects of sexuality in persons with intellectual disabilities (ID) is their capacity to provide informed consent. To some extent this capacity is mediated by the receipt of knowledge to enable these persons to provide consent, so as to avoid manipulation by others. For persons with ID there is a difficult balance to be struck between empowering people to claim their sexual rights and protecting them from abuse. Murphy and O’Callaghan assessed 60 adults with intellectual disabilities and 60 young people presumed in law able to consent in terms of their sexual knowledge and vulnerability to abuse.<sup>71</sup> Adults with intellectual disabilities were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships. Nevertheless, some adults with intellectual disabilities scored highly on all measures, especially if they had relatively high IQs and had had sex education.

Braathen et al. note that “several studies have found that young people with disabilities, especially with learning/ developmental/ intellectual disabilities, are overprotected by their carers, and are subject to great degrees of control and supervision. Young people with intellectual disabilities in particular are often seen and treated as ‘eternal children’, underestimated, giving parents legitimacy for overprotection and control. This leads to lack of privacy and independence for these young people to explore romance and sexuality, and contributes to undermining their sexual development.” Among the studies

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71 Murphy, G. H. and A. O’Callaghan (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships [Developmental Disorders & Autism 3250]. *Psychological Medicine* 34 (7): 1347–1357.

that they cite are Maia,<sup>72</sup> McKenzie and Swartz,<sup>73</sup> and Wilkinson and Raczka.<sup>74</sup> Among the many delicate problems surrounding sexual and reproductive health and rights, one that is frequently brought up is navigating the risks of HIV and AIDS.

Currently the tendency is to promote such “supported/ assisted decision-making processes” in order to maximize the amount of participation that persons with disabilities can have in their own health care and decisions about their sexuality.<sup>75</sup> Supported decision-making assists individuals with intellectual disabilities to make and communicate to others decisions about one’s life. It reflects the consultative, relational manner in which most people make decisions – with support from trusted friends, advisors and family members. However, there is considerable debate within the legal and medical professions on where the borders between these modalities should be drawn.

A relatively small number of studies have focused on the concept of self-advocacy. Friedman et al. examined how persons with intellectual and developmental disabilities define and experience sexuality in the context of their identities as self-advocates.<sup>76</sup> Self-advocates described sexual self-advocacy as relating to knowing and respecting themselves, respect for others, choices, speaking up, having their rights respected, getting information, healthy relationships and interdependence. They also explained “facilitators” that would increase their sexual self-advocacy such as expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counselling and developing opportunities for sexual expression.

Black and Kammes examined existing research on what persons with intellectual disability think and feel about their sexual lives, as a way to enable families and professionals to offer a more person-centered approach to education and support.<sup>77</sup> They combined the results of 16 qualitative studies from Europe and Australia, China and the United States, in which 271 participants with an intellectual disability were interviewed individually or in focus groups about their feelings and experiences regarding intimate relationships. Results revealed two competing themes of control and desire. Participants across studies desired friendships and close interpersonal relationships, yet were restricted from developing these relationships by policies, programme staff and family members.

McCarthy reviewed five studies from Australia, the United States and the United Kingdom in which women spoke in focus groups about their intimate relationships and

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72 Maia, A. C. B. (2016). Sexuality experience as from report of people with intellectual disability. [Vivência da sexualidade a partir do relato de pessoas com deficiência intelectual] *Psicologia em Estudo* 21(1): 77-88.

73 McKenzie, J. A., and L. Swartz (2011). The shaping of sexuality in children with disabilities: A Q methodological study. *Sexuality and Disability* 29 (4): 363-376.

74 Wilkinson, V. J.; K. Theodore and R. Raczka (2015). ‘As normal as possible’: sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability* 33(1): 93-105.

75 See, for example, Kohn, N. A.; J. A. Blumenthal and A. T. Campbell (2012). Supported decision-making: A viable alternative to guardianship. *Penn St. L. Rev.*, 117: 1111.

76 Friedman, Carli; Catherine K. Arnold; Aleksa L. Owen and Linda Sandman (2014). “Remember Our Voices are Our Tools:” Sexual Self-advocacy as Defined by People with Intellectual and Developmental Disabilities. *Sexuality and Disability* 32: 515–532.

77 Black, Rhonda S. and Rebecca R. Kammes (2019). Restrictions, Power, Companionship, and Intimacy: A Metasynthesis of People With Intellectual Disability Speaking About Sex and Relationships. *Intellect Dev Disabil* 57 (3): 212-233.



sexual lives.<sup>78</sup> She found that, though not universal, it is negative perceptions, negative experiences, thwarted ambitions and abuse that dominate the narratives of women with intellectual disability when they are asked about their sexual lives. Therefore, women with intellectual disability need help in developing their self-esteem and agency, sex education that emphasizes female sexual pleasure and assessing risk, as well as peer support. Wider structural, social and service-level changes are also needed, along with suggestions for enhancing women's ability to exercise a greater degree of control over their sexual lives. For example, a recent study in Ethiopia found that only 60 per cent of young persons with disabilities believed that a wife has a right to refuse unprotected sex with her husband.<sup>79</sup>

Several studies note that most persons with intellectual disabilities are sexually active and need information on how to manage their sexuality.<sup>80,81</sup> More generally, Haynes et al. found that sexual activity among women with disability is about the same as among women without disability.<sup>82</sup> Yet more than half of women with intellectual disabilities have been told they should not have a child.<sup>83</sup> McClelland et al. note that youth with intellectual disabilities

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78 McCarthy, M. (2014). Women with intellectual disability: Their sexual lives in the 21st century. *Journal of Intellectual & Developmental Disability* 39 (2): 124–131.

79 Kassa, T. A. et al. (2016). Sexual and Reproductive Health of Young Persons with Disability in Ethiopia: A study on knowledge, attitude and practice: A cross-sectional study. *Globalisation and Health* 12(5).

80 Brkić-Jovanović N.; V. Runjo; D. Tamaš; S. Slavković and V. Milankov (2021). Persons with intellectual disability: Sexual behaviour, knowledge and assertiveness. *Slov. J. Public Health* 60: 82–89.

81 Olaleye, A. O.; O. A. Anoemuah; O. A. Ladipo; G. E. Delano and G. F. Idowu (2007). Sexual behaviours and reproductive health knowledge among in-school young people with disabilities in Ibadan, Nigeria. *Health Educ.* 107: 208–218.

82 Haynes, R. M.; S. L. Boulet; M. H. Fox; D. D. Carroll; E. Courtney-Long and L. Warner (2018). Contraceptive use at last intercourse among reproductive-aged women with disabilities: An analysis of population-based data from seven states. *Contraception*, 97 (6): 538–545.

83 UNFPA (2022). Advocacy brief: Disability and the Right to Bodily Autonomy. Available at <https://www.unfpa.org/resources/advocacy-brief-disability-and-right-bodily-autonomy>.

are discovering and exploring their sexuality, but experience more external controls over their autonomy than others their age.<sup>84</sup> Gascon et al. examined the themes in the scientific literature from 1990 to 2007 that focused on adolescents with intellectual disabilities and found that sexual life is in fifth position on a list of 21 themes.<sup>85</sup> Shandra and Chowdhury suggest that having mild intellectual disabilities increases the likelihood of having first sexual intercourse with a stranger versus a steady dating partner.<sup>86</sup> These results also may reflect the increased likelihood for women with intellectual disabilities to be victims of sexual assault. Girls with multiple conditions or severe intellectual disabilities who do not use contraception at first sexual intercourse are also much more likely to want a pregnancy. In a later article, Shandra, Shameem and Ghori report that boys with learning disabilities are more likely to report very early sexual debut (between ages 12 and 14 years) and to talk a lot about birth control, but be less likely to use condoms if they do use contraceptive methods.<sup>87</sup> Gender and type of disabling condition intersect to shape the context of first sexual intercourse. Evaluation of training resources for the sexual education of people with moderate to severe ID found a lack of suitable materials and assessments.

Deffew et al. found that caregivers generally recognized that love is a human desire, including for persons with ID, but reflected how the lack of open discussion had repressed the expression of sexuality of persons with intellectual disabilities.<sup>88</sup> They detailed how religious teachings were very much part of the founding culture, and these viewpoints still existed in services today. Staff reported that among issues around people with ID, sexuality was often about negative experiences. A similarly ambivalent attitude has been reported in other studies.<sup>89,90,91</sup> Morales et al. reported more open attitudes among Mexican than among French adults.<sup>92</sup> Pajot, Muñoz and Nacher found attitudes among adults to be strongly related to general political views, with left-wing adults being more open than religious persons.<sup>93</sup> Winarni et al. reported that attitudes in Indonesia are still quite conservative.<sup>94</sup>

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84 McClelland, A.; S. Flicker; D. Nepveux; S. Nixon; T. Vo; C. Wilson et al. (2012). Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality* 59(6): 808-819.

85 Gascon, Hubert; Marie-Claire Haelewyck; Isabelle Simões Loureiro; Marie-Josée Bibeau and Élise Milot (2010). Retard mental et adolescence: examen des thèmes abordés dans les écrits scientifiques. In: *Adolescence et retard mental*: Chapter 1.

86 Shandra C.L. and A. R. Chowdhury (2012). The first sexual experience among adolescent girls with and without disabilities. *J. Youth Adolesc.* 41: 515–532.

87 Shandra C.L.; M. Shameem and S.J. Ghori (2016). Disability and the context of boys' first sexual intercourse. *J. Adolesc. Health* 58:302–309.

88 Deffew A.; B. Coughlan; T. Burke and E. Rogers (2022). Staff member's views and attitudes to supporting people with an intellectual disability: A multi-method investigation of intimate relationships and sexuality. *J. App. Res. Intellect. Disabil.* 35: 1049–1058.

89 Gilmore L. and B. Chambers (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *J. Intellect. Dev. Disabil.* 35: 22–28.

90 Parchomiuk M. (2012). Specialists and sexuality of individuals with disability. *Sex. Disabil.* 30: 407–419.

91 Parchomiuk M. (2013). Model of intellectual disability and the relationship of attitudes towards the sexuality of persons with an intellectual disability. *Sex. Disabil.* 31: 125–139.

92 Morales, G. E. M.; E. O. L. Ramirez; M. Esterle; M. T. M. Sastre and E. Mullet (2010). Judging the acceptability of sexual intercourse among people with learning disabilities: A Mexico-France comparison. *Sex. Disabil.* 28: 81–91.

93 Pajot E.; M. T. Muñoz and Nacher (2015). Mapping people's views regarding childbearing among people with learning difficulties. *Sex. Disabil.* 33: 447-456.

94 Winarni T. I.; H. Hardian; S. Suharta and A. Ediaty (2018). Attitudes towards sexuality in males and females with intellectual disabilities: Indonesia setting. *J. Intellect. Disabil.-Diagn. Treat.* 6: 43–48.

## Right to live a life free from violence

Apart from violence in the limited sense of the word used by DHS, which is defined in the Methodology section and discussed in the previous section, freedom from violence also involves issues of institutional violence, including from health providers. Institutional violence can take many forms, such as the removal of a ramp or mobility devices, removing or controlling communication aids, refusal by a caregiver to assist with daily living (such as bathing, dressing and eating), denial of food or water, or threat of engaging in any of those acts. Women with disabilities often experience controlling behaviours from intimate partners, caretakers or others that can be justified as protection, but in fact prevent them from exercising their right to bodily autonomy. Prominent among these concerns is the issue of forced sterilization. This is often framed as an issue of the right to receive information and make decisions on body, health and sexuality, but it can also be considered an issue of the right to live a life free from violence. Women with disabilities, particularly intellectual disabilities, are subject to forced sterilization, abortion and use of contraceptives against their will because others say it is best for them. Not only are their reproductive rights violated, but where victims are no longer at risk of getting pregnant, they are also made easier targets for sexual abusers.

Even today, the practice of forced sterilization of persons with disabilities still finds legal support in several laws and decisions that have been taken by courts in several countries. The National Women's Law Center provides a recent overview of the legislation in the different states of the United States and examples violations of human rights by the court system. A similar critique on legal practices in Australia was published some years ago. Steele and Goldblatt also use Australia as a case study in the continued legal support for sterilization and other coercive responses to menstruation.<sup>95</sup> Durojaye discusses the decision of the Namibian Supreme Court in *Government of Namibia v LM* and argues that the court fails to consider involuntary sterilization as a form of human rights violation, particularly violence against women.<sup>96</sup> The article contends that given the attendant mental, physical and emotional trauma a woman may suffer upon undergoing forced sterilization, this would amount to an act of violence against women as recognized under international human rights law. Forced and coerced sterilization against marginalized women has also been documented in countries such as the Czech Republic, Dominican Republic, Hungary, India, Kenya, Mexico, Slovakia, South Africa, Swaziland, Uzbekistan and Venezuela.

## Sterilization

Within the medical profession, the issue of sterilization of women with disabilities is controversial and it is only relatively recently that it has become framed as a human rights issue. In a study from Australia, Gilmore and Malcolm found that doctors generally considered

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95 Steele, Linda and Beth Goldblatt (2020). The Human Rights of Women and Girls with Disabilities: Sterilization and Other Coercive Responses to Menstruation. In: *The Palgrave Handbook of Critical Menstruation Studies*: 77–91.

96 Durojaye, Ebenezer (2017). Involuntary Sterilisation as a Form of Violence against Women in Africa. *Journal of Asian and African Studies* Vol. 53, Issue 5.

sterilization a desirable practice for both men and women with intellectual disabilities.<sup>97</sup> Older doctors reported more support for sterilization. In a similar study in New Zealand, the majority of participants from medical interest groups indicated that a procedure might be warranted for both men and women with ID within certain circumstances. For example, for men with intellectual disability, this might include lack of control over sexual responses and individual choice. For women with ID, circumstances might include managing sexual desire, fertility control, unwanted pregnancy and vulnerability to abuse. In a qualitative study in Taiwan that explored decision-making regarding sterilization for women with ID living with their families, including how such decisions are made and who is involved in the decision-making, Chou and Lu<sup>98</sup> concluded that with respect to sexuality and body images among women with intellectual deficiency, concern should exist among society in general and among professionals in particular, regarding human rights. In a review of the literature up to 2002 on the attitudes of parents and teachers of persons with intellectual disabilities, mostly in Canada and the United States, Aunos and Feldman concluded that, despite the ban on involuntary sterilization, many parents and teachers of persons with ID still support it as a form of contraception, especially for persons with severe ID.<sup>99</sup> Likewise, attitudes towards parenting by persons with intellectual disabilities remain negative, and these attitudes may adversely affect the provision of competency-enhancing supports and services for parents with ID and their children.

Among the quantitative studies of the subject, Li et al. found, based on a secondary analysis of nationally-representative data from the United States National Survey of Family Growth 2011–15, that female sterilization rates were higher among women with cognitive (22.1 per cent) and non-cognitive disabilities (24.7 per cent) than among women without disabilities (14.8 per cent).<sup>100</sup> After adjusting for sociodemographic covariates, women with cognitive disabilities had significantly higher odds of female sterilization (odds ratio of 1.54) and hysterectomy (odds ratio of 2.64) than women without cognitive disabilities. Women with cognitive disabilities also underwent sterilization at significantly younger ages (average of 27.3 years) than women with non-cognitive disabilities (28.3 years) and women without any disability (29.8 years). Using the same data source, Mosher et al. also found that there were significant differences by disability status in use of sterilization among White and Black women. Black women with disability were particularly likely to use sterilization compared to Black women without a disability (41 versus 23 per cent, respectively). Márquez-González et al. noted that in public hospitals in Mexico City non-therapeutic hysterectomy continues to be one common procedure

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97 Gilmore L., and L. Malcolm (2014). "Best for everyone concerned" or "Only as a last resort"? Views of Australian doctors about sterilisation of men and women with intellectual disability. *J. Intellect. Dev. Disabil.* 39: 177–187.

98 Chou YC, Lu ZY. Deciding about sterilisation: perspectives from women with an intellectual disability and their families in Taiwan. *J Intellect Disabil Res.* 2011 Jan;55(1):63-74. doi: 10.1111/j.1365-2788.2010.01347.x. Epub 2010 Dec 1. PMID: 21121994.

99 Aunos M, Feldman M A. Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *J Appl Res Intellect Disabil* 2002; 15: 285-96.

100 Li, Henan; Monika Mitra; Justine P. Wu; Susan L. Parish; Anne Valentine; and Robert S. Dembo (2018). Female Sterilization and Cognitive Disability in the United States, 2011–2015. *Obstet Gynecol.* 132 (3): 559–564.



performed in females with ID.<sup>101</sup> In cultures where contradicting a physician is considered disrespectful parents/carers may assume a “passive patient” role.<sup>102</sup> Also, presenting hysterectomy as a safe surgical procedure and having preventive benefits, clearly might have an influence on the parent’s choice.

Particularly relevant from the viewpoint of bodily autonomy are the issues of forced marriage and forced adoption. Not many studies exist on these subjects, but there are some. Clawson et al. found that the risk of forced marriage in the United Kingdom is higher for persons with learning disabilities.<sup>103</sup> The main reason to perform them is the desire on the part of (ageing) parents to secure a reliable carer for their son or daughter. Around half of all forced marriages take place when the victim is aged between 16 and 21. Forced marriage alludes to it being an issue affecting predominantly young females though recent data shows men with learning disabilities are equally likely to be forced to marry. Brown et al. found that 1 in 20 newborns of women with intellectual and developmental disabilities (IDD) were discharged to child protective services immediately after the birth hospitalization.<sup>104</sup> Women with IDD were also found to have a particularly high risk for custody loss. Mayes and Llewellyn carried out a qualitative study on the daily life narratives of seven mothers with ID following the involuntarily removal of their children.<sup>105</sup> For most mothers, having a child removed was not a one-off experience. The serial nature of the experience yielded three different narratives, lived out in different ways. In some cases, women told a different narrative for each of their removed children. All women remained focused on their children in care.

## Right to access sexual and reproductive health information and services

Forced sterilization of women with a disability who are intellectually able to make their own decisions in the matter is a blatant violation of human rights – yet there are many more subtle cases, where health providers overstep their authority by inducing women to make certain reproductive health decisions that only they should be making or by providing insufficient information to make such a decision possible. In one study in the United States, women with disabilities described physicians making unilateral decisions about the contraceptive method the women should use. Patients reported a perceived taboo on discussing contraception, and clinician lack of support for informed decision-making (not discussing options, making decisions for women about the appropriate

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101 Márquez-González H.; E. Valdez-Martínez and M. Bedolla (2021). Clinical, epidemiologic and ethical aspects of hysterectomy in young females with intellectual disability: A multi-centre study of public hospitals in Mexico City. *Front. Public Health* 9:746399.

102 Mosher, William; Rosemary B. Hughes; Tina Bloom; Leah Horton; Ramin Mojtabai and Jeanne L. Alhusen (2018). Contraceptive use by disability status: new national estimates from the National Survey of Family Growth. *Contraception* 97 (6): 552–558.

103 Clawson R.; A. Patterson; R. Fyson and M. McCarthy (2020). The demographics of forced marriage of people with learning disabilities: Findings from a national database. *J. Adult Prot.* 22: 59–74.

104 Brown H. K.; L. A. Potvin; Y. Lunskey and S. N. Vigod (2018). Maternal intellectual or developmental disability and newborn discharge to protective services. *Pediatrics*. 142:e20181416.

105 Mayes R. and G. Llewellyn (2012). Mothering differently: Narratives of mothers with intellectual disability whose children have been compulsorily removed. *J. Intellect. Dev. Disabil.* 37: 121–130.



method for them).<sup>106</sup> A qualitative study based on 16 interviews concluded that women with physical disabilities experience barriers to contemplating pregnancy including inadequate information on pregnancy and reproductive health care that affects their decision-making regarding pregnancy and parenting.<sup>107</sup> All health-care providers should talk to patients with disabilities about family planning and address possible barriers to contemplating pregnancy.

Ledger et al. showed that, within their sample, decisions on contraception were made by general practitioners, followed by mothers.<sup>108</sup> Women with learning disabilities usually begin to take contraception when they are not sexually active to prevent pregnancies (related to fear of abuse) and to manage menstruation. By far the most widely used form of contraception was a contraceptive implant. Wu et al. also found that women with intellectual and developmental disabilities were more likely to use long-acting reversible contraception (LARC).<sup>109</sup> Caregivers, including family members and residential facility staff play an important role in contraceptive selection and access. They found evidence that caregivers request contraception on behalf of women with intellectual and developmental disabilities for reasons other than contraception.

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106 Horner-Johnson, W.; K. A. Klein; J. Campbell, and J. M. Guise (2022). It Would Have Been Nice to Have a Choice: Barriers to Contraceptive Decision-Making among Women with Disabilities. *Women's Health Issues*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/35148954>.

107 O'Connor-Terry, Carly and John Harris (2022). Pregnancy decision-making in women with physical disabilities. *Disabil Health* 15 (1):101176.

108 Ledger S.; S. Earle; E. Tilley and J. Walmsley (2016). Contraceptive decision-making and women with learning disabilities. *Sexualities* 19: 698–724.

109 Wu J.; J. Zhang; M. Mitra; S. L. Parish and G. K. M. Reddy (2018). Provision of moderately and highly effective reversible contraception to insured women with intellectual and developmental disabilities. *Obs. Gynec.* 132:565.

Taouk et al. identified the following barriers to the contraceptive choice of women with disabilities: (1) ability to utilize contraception; (2) decision-making capacities for contraception and sex; (3) consent to irreversible means of contraception; (4) patient understanding of contraception risks and benefits; (5) patient understanding of sexually transmitted infection or pregnancy prevention.<sup>110</sup> In a recent study, 20 per cent of women with disabilities had never used any sexual and reproductive health service.<sup>111</sup>

Women with disabilities experience a range of violations of their sexual and reproductive rights. Devine reported on the W-DARE project (Women with Disability taking Action on Reproductive and sexual health) in the Philippines, a three-year participatory action research programme designed to understand the sexual and reproductive health experiences and needs of women with disabilities, and to improve access to quality sexual and reproductive health, including violence response services, for women with disabilities in the Philippines.<sup>112</sup> In response to the need for more information about sexual and reproductive health and greater access to services, the W-DARE team developed and implemented a pilot intervention focused on peer-facilitated Participatory Action Groups (PAGs) for women with disabilities.

In qualitative interviews with Agaronnik et al., 42 physicians indicated that intellectual disability can pose challenges to providing sexual and reproductive health care in four areas: (1) communication; (2) routine preventive care; (3) contraception and sterilization; and (4) conception and parenthood.<sup>113</sup> Observations raised concerns about equity of access to reproductive care for women with ID. The authors concluded that these observations indicate the existence of attitudes that might compromise reproductive care for women with ID, suggesting that gaps remain in ensuring reproductive rights of women with ID.

Taouk, Fialkow and Schulkin identified some of the gaps in the training of obstetricians that would help them to better deal with the reproductive health needs of women with disabilities.<sup>114</sup> Conder et al. noted that there are barriers to successful planning for both pregnancy and parenthood.<sup>115</sup> However, with the right support, these parents can provide a secure and loving environment for their child. Enabling informed decisions about becoming a parent could increase the number of parents who successfully raise their own child. They highlighted the experiences of six parents are used to illustrate issues relevant to informed decision-making, including knowledge of contraception, the development of

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110 Taouk, L. H.; M. F. Fialkow and J. A. Schulkin (2018). Provision of reproductive healthcare to women with disabilities: A survey of obstetrician-gynecologists' training, practices, and perceived barriers. *Health Equity* 2: 207–215.

111 DeBeaudrap P; C. Mouté; E. Pasquier; M. Mac-Seing; P. U. Mukangwije and G. Beninguisse G (2019). Disability and Access to Sexual and Reproductive Health Services in Cameroon: A Mediation Analysis of the Role of Socioeconomic Factors. *Int J Environ Res Public Health*.

112 Devine, A.; R. Ignacio; K. Prenter; L. Temminghoff; L. Gill-Atkinson; J. Zayas; M. J. Marco and C. Vaughan (2017). "Freedom to go where I want": improving access to sexual and reproductive health for women with disabilities in the Philippines. *Reprod Health Matters* 25 (50): 55-65.

113 Agaronnik N.; E. Pendo; T. Lagu; C. DeJong; A. Perez-Caraballo and L. I. Iezzoni (2020). Ensuring the reproductive rights of women with intellectual disability. *J. Intellect. Dev. Disabil.* 45: 365–376.

114 Taouk, L. H.; M. F. Fialkow and J. A. Schulkin (2018). Provision of reproductive healthcare to women with disabilities: A survey of obstetrician-gynecologists' training, practices, and perceived barriers. *Health Equity* 2: 207–215.

115 Conder, J.; B. Mirfin-Veitch; J. Sanders and M. Munford (2011). Planned pregnancy, planned parenting: Enabling choice for adults with a learning disability [Developmental Disorders & Autism 3250]. *British Journal of Learning Disabilities*, 39 (2): 105–112.

parenting skills and the importance of social support. Through their contrasting stories, a combination of family support and appropriately responsive services was identified as critical to the development of a positive parenting context.

Biel et al. discuss the complications of caesarean deliveries in women with ID.<sup>116</sup> They found higher proportions of C-sections deliveries among women with ID. They also identified a pattern of unlaboured caesarean deliveries that do not appear to be medically indicated. Gleason et al. identified a higher risk of almost all pregnancy complications, obstetric interventions and adverse outcomes in women with ID.<sup>117</sup> They face barriers to care, including financial barriers, and report negative reactions towards their pregnancy, which extends to health care practitioners and may affect the quality of care provided and lead to refusal of care for these women. Murthy et al. found that Indian women with disabilities have a significantly lower pregnancy rate compared to women without a disability.<sup>118</sup> They have higher risk of comorbidities like diabetes and depression. Interestingly, however, they also found that antenatal and natal care were similar for women with and without a disability.

Potvin et al. found evidence of prejudicial attitudes of caregivers inhibited women with persons with intellectual and developmental disabilities from disclosing their pregnancies and needs.<sup>119</sup> Perinatal informational support appeared to be especially influenced by information format, the women's level of autonomy and the nature of caregiver involvement. Redshaw et al. also found that women with learning disability had a higher incidence of C-section, which seemed to be a planned procedure.<sup>120</sup> During pregnancy, they reported being spoken in a way they could not understand. During labour, their partner was rarely welcomed. Few participants reported being involved in decisions about their care.

Wickström et al. found that mothers with ID were younger and cohabited less often with the child's father.<sup>121</sup> The children born to mothers with ID were more often born premature and were at a greater risk of being diagnosed with mental health problems and epilepsy in early childhood. Furthermore, children of mothers with ID had an increased risk of being exposed to injuries, violence and child abuse. It was found that children of mothers with ID had a three times higher risk of being victims of violence and abuse.

A considerable part of the literature on this subject is dedicated to sexuality education and appropriate ways to implement it in the case of persons with intellectual

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116 Biel F.; B. Darney; A. Caughey and W. Horner-Johnson (2020). Medical indications for primary cesarean delivery in women with and without disabilities. *J. Matern. -Fetal Neonatal Med.* 33: 3391–3398.

117 Gleason J.L.; J. Grewal J.; Z. Chen; A. N. Cernich and K. L. Grantz (2021). Risk of adverse maternal outcomes in pregnant women with disabilities. *JAMA Netw. Open.* 4:e2138414.

118 Murthy, G. V. S.; N. John; J. Sagar; B. R. Shamanna; C. Noe; F. Soji et al. (2014). Reproductive health of women with and without disabilities in South India, the SIDE study (south India disability evidence) study: A case control study. *BMC Women's Health* 14 (1).

119 Potvin L. A.; R. D. Lindenbach; H. K. Brown and V. Cobigo (2020). Preparing for motherhood: Women with intellectual disabilities on informational support received during pregnancy and knowledge about childbearing. *J. Dev. Disabil.* 25: 1–15.

120 Redshaw M.; R. Malouf; H. Gao and R. Gray (2013). Women with disability: The experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth* 13:174.

121 Wickström M.; B. Höglund; M. Larsson and M. Lundgren (2017). Increased risk for mental illness, injuries, and violence in children born to mothers with intellectual disability: A register study in Sweden during 1999-2012. *Child Abus. Negl.* 65:124-131.

disabilities.<sup>122,123,124,125,126,127,128,129</sup> More specifically, some studies are dedicated to the effectiveness of so-called Easyread methods that use simplified language in order to convey basic messages about sexuality and bodily autonomy.<sup>130,131</sup> Brown and McCann, in a literature review of 23 studies on the subject, concluded that adults with ID need education and support to express their sexuality and to meet individual needs.<sup>132</sup> In another literature review of 11 studies on the individual views and opinions of families and direct care support workers, the same authors concluded that families and direct care support workers have specific support and education needs. Future health-care initiatives need to be developed that are fully responsive to the identified concerns and requirements of families and direct care support workers.<sup>133</sup>

In addition to sexuality education, the second most common theme for research with respect to the sexuality of persons with ID was attitudes of caregivers towards the sexuality of persons with ID. De Wit et al. conducted a qualitative systematic literature review of 31 articles on the sexuality of persons with ID and identified these as the most common themes.<sup>134</sup> They noted that, despite a general acceptance of the sexual rights of people with ID, certain forms of sexuality were approached more cautiously. Those support staff and relatives holding rather restrictive attitudes appear to emphasize sexual risks. Finally, support staff and relatives stressed the importance of providing sex education and support for people with ID, while, simultaneously, expressing insecurity over the subject.

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122 Murphy C.; S. Lincoln; S. Meredith; E. M. Cross and D. Rintell (2016). Sex education and intellectual disability: Practices and insight from pediatric genetic counselors. *J. Genet. Couns.* 25: 552–560.

123 Goli, S.; M. Noroozi; and M. Salehi (2021). Comparing the effect of two educational interventions on mothers' awareness, attitude, and self-efficacy regarding sexual health care of educable intellectually disabled adolescent girls: A cluster randomized control trial. *Reprod. Health* 18: 54.

124 Gutiérrez-Bermejo B.; N. Flores; P. J. Amor and C. Jenaro (2021). Evidences of an implemented training program in consensual and responsible sexual relations for people with intellectual disabilities. *Int. J. Env. Res. Public Health* 18: 2323.

125 Barnard-Brak, L.; M. Schmidt; S. Chesnut; T. Wei and D. Richman (2014). Predictors of access to sex education for children with intellectual disabilities in public schools. *Intellectual & Developmental Disabilities* 52(2): 85–97.

126 Frawley, P. and A. O'Shea (2020). 'Nothing about us without us': Sex education by and for people with intellectual disability in Australia. *Sex Education* 20 (4): 413–424.

127 Murray, L. B. (2019). Sexual health education for adolescents with developmental disabilities. *The Health Education Journal* 78 (8): 1000–1011.

128 McDaniels, B., and A. Fleming (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability*, 34, 1–11.

129 Wolfe, P. S.; J. L. Wertz; S. Domire Monaco; S. Gardner and S. Ruiz (2019). Review of sociosexuality curricular content for individuals with developmental disabilities 34 (3): 153–162.

130 Chinn, D. and C. Homeyard (2017). Easy read and accessible information for people with intellectual disabilities: Is it worth it? A metanarrative literature review. *Health Expectations* 20(6): 1189–1200.

131 Sutherland, R. J. and T. Isherwood (2016). The evidence for easyread for people with intellectual disabilities: A systematic literature review. *Journal of Policy and Practice in Intellectual Disabilities* 13 (4): 297–310.

132 Brown, Michael and Edward McCann (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Res Dev Disabil.* 74: 124-138.

133 Brown, Michael and Edward McCann (2019). The views and experiences of families and direct care support workers regarding the expression of sexuality by adults with intellectual disabilities: A narrative review of the international research evidence. *Res Dev Disabil.* 90: 80-91.

134 De Wit, Wouter; Wietske M. W. J. Oorsouw and Petri J. C. M. Embregts (2022). Sexuality, Education and Support for People with Intellectual Disabilities: A Systematic Review of the Attitudes of Support Staff and Relatives. *Sexuality and Disability* 40: 315–346.

## Right to a life without discrimination

Negative attitudes towards persons with disabilities are at the root of discriminatory laws, policies and practices. In some traditional cultures, disability is considered a “curse”. Hanass-Hancock found reduced value as a spouse and negated sexual identity in South Africa.<sup>135</sup> Paradoxically, the effect may also be opposite. In South Africa, gender norms about women needing to be submissive may result in women who are deaf being sought after as an ideal “submissive” spouse. In the Southern Asian context, in Bangladesh, Hasan et al. suggest the stigma associated with disability may lead to the need to pay a higher dowry.<sup>136</sup> However, there may be cultural and gender norms making some disabilities less desirable than others. Adolescents with disabilities feel socially isolated and rejected and have low general and sexual self-esteem.<sup>137,138,139,140</sup> Girls in particular are more likely to be bullied.<sup>141</sup> Sometimes, the disability stigma makes young women accept a partner who may mistreat them or accept unsafe sex, just to have a partner.<sup>142,143</sup>



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- 135 Hanass-Hancock, J. (2009). Interweaving conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa. *Sexuality and Disability* 27(1): 35-47.
- 136 Hasan, T., Muhaddes, T., Camellia, S., Selim, N., & Rashid, S. F. (2014). Prevalence and experiences of intimate partner violence against women with disabilities in Bangladesh: Results of an explanatory sequential mixed-method study. *Journal of Interpersonal Violence* 29(17): 3105-3126.
- 137 Czapla, K. and W. Otrębski (2014). Sexual self-esteem and sexual needs of young adults with cerebral palsy. *Health Psychology Report* 2(4): 247-255.
- 138 Esmail, S.; K. Darry; A. Walter and H. Knupp (2010). Attitudes and perceptions towards disability and sexuality. *Disability and Rehabilitation* 32(14): 1148-1155.
- 139 Linton, K. F., and H. A. Rueda (2014). Experiences with pregnancy of adolescents with disabilities from the perspectives of the school social workers who serve them. *Health & Social Work* 39(2): 92-100.
- 140 Heller, M. K.; S. Gambino; P. Church; S. Lindsay; M. Kaufman and A. C. McPherson (2016). Sexuality and relationships in young people with spina bifida and their partners. *Journal of Adolescent Health*, 59(2), 182-188.
- 141 Eisenberg, M. E.; A. L. Gower; B. J. McMorris and M. M. Bucchianeri (2015). Vulnerable bullies: perpetration of peer harassment among youths across sexual orientation, weight, and disability status. *American Journal of Public Health* 105(9): 1784-1791.
- 142 Chappell, P. (2014). How Zulu-speaking youth with physical and visual disabilities understand love and relationships in constructing their sexual identities. *Culture, Health & Sexuality* 16(9): 1156-1168.
- 143 Wazakili, M.; R. Mpofu and P. Devlieger (2006). Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: A case study. *Sexuality and Disability* 24(2): 77-88.



## 5. Results

### Who are women with disabilities? Socio-demographic characteristics

Tables 1 and 2 show the prevalence of disability by functional domains for women across the six countries in this study. The prevalence of disability ranges from 1 per cent in Mali to 4.4 per cent in Pakistan. The three most prevalent types of disabilities are visual disability, mobility disability and cognitive disability. Table 1 refers to the entire sample of women, which is appropriate for the analysis of bodily autonomy. Table 2 refers only to the women who answered the domestic violence module, which is the correct reference for the analysis of disability and violence. The presence of disability is defined as having “a lot of difficulty” or “cannot perform it at all” in performing a given function.

**Table 1: Prevalence of disability by functional domain and country for the total sample**

| Type of disability | Haiti (N=14,371) |     | Mali (N=10,519) |     | Pakistan (N=12,364) |     | Rwanda (N=14,634) |     | South Africa (N=8,514) |     | Uganda (N=18,506) |     |
|--------------------|------------------|-----|-----------------|-----|---------------------|-----|-------------------|-----|------------------------|-----|-------------------|-----|
|                    | Per cent         | n   | Per cent        | n   | Per cent            | n   | Per cent          | n   | Per cent               | n   | Per cent          | n   |
| Any                | 1.45             | 208 | 1.02            | 108 | 4.41                | 545 | 3.58              | 524 | 2.84                   | 242 | 2.54              | 470 |
| Vision             | 0.74             | 106 | 0.32            | 34  | 1.63                | 202 | 1.82              | 266 | 1.24                   | 105 | 0.10              | 18  |
| Hearing            | 0.09             | 12  | 0.19            | 20  | 0.36                | 44  | 0.44              | 65  | 0.33                   | 28  | 0.01              | 2   |
| Communication      | 0.03             | 5   | 0.03            | 3   | 0.06                | 7   | 0.08              | 12  | 0.10                   | 9   | 0.11              | 20  |
| Cognitive          | 0.42             | 61  | 0.12            | 12  | 0.68                | 83  | 0.74              | 108 | 0.58                   | 49  | 1.38              | 255 |
| Mobility           | 0.33             | 47  | 0.40            | 42  | 2.40                | 297 | 0.87              | 128 | 0.88                   | 75  | 1.14              | 210 |
| Self-care          | 0.09             | 13  | 0.07            | 7   | 0.36                | 45  | 0.15              | 22  | 0.15                   | 12  | 0.14              | 26  |

**Table 2: Prevalence of disability by functional domain and country for the sample of women who answered the module on domestic violence**

| Type of disability | Haiti (N=6,321) |    | Mali (N=3,784) |    | Pakistan (N=3,303) |     | Rwanda (N=2,788) |    | South Africa (N=4,611) |     | Uganda (N=9,232) |     |
|--------------------|-----------------|----|----------------|----|--------------------|-----|------------------|----|------------------------|-----|------------------|-----|
|                    | Per cent        | n  | Per cent       | n  | Per cent           | n   | Per cent         | n  | Per cent               | n   | Per cent         | n   |
| Any                | 1.29            | 81 | 1.14           | 43 | 4.07               | 134 | 2.62             | 73 | 2.53                   | 117 | 2.47             | 228 |
| Vision             | 0.76            | 48 | 0.37           | 14 | 1.47               | 47  | 1.36             | 38 | 1.01                   | 47  | 0.06             | 5   |
| Hearing            | 0.08            | 5  | 0.17           | 6  | 0.17               | 6   | 0.41             | 11 | 0.27                   | 13  | 0.03             | 2   |
| Communication      | 0.01            | 1  | 0.00           | 0  | 0.16               | 5   | 0.03             | 1  | 0.04                   | 2   | 0.10             | 9   |
| Cognitive          | 0.23            | 14 | 0.20           | 7  | 0.65               | 22  | 0.49             | 14 | 0.59                   | 27  | 1.29             | 119 |
| Mobility           | 0.37            | 24 | 0.43           | 16 | 2.11               | 70  | 0.64             | 18 | 0.83                   | 38  | 1.07             | 99  |
| Self-care          | 0.09            | 6  | 0.03           | 1  | 0.32               | 11  | 0.15             | 4  | 0.15                   | 7   | 0.12             | 11  |

Table 3 presents the bivariate analyses of the association between basic background characteristics and disability. All the values shown in these tables are significant, i.e. they are statistically different from 0.

As expected, the prevalence is higher for older women, with the exception of Mali where there was no statistical significance (at the 5 per cent level of significance). Regarding education, there were only significant differences for women with at least secondary



education in Rwanda and Uganda (significance level of the differences is not shown here). Wealth status and place of residence (urban/rural) were not significant for differences in the prevalence of disabilities. In Pakistan and Rwanda, women formerly in union had a higher prevalence of disabilities than women currently in union. This could be due to the fact that women with disabilities are more likely not to be in union anymore, but it may also be because women formerly in union are, on average, older than women currently in union.

**Table 3: Prevalence of any disability by basic demographic and socioeconomic characteristics in each country (15–49 age group) for the total sample**

| Population groups      | Haiti<br>(N=14,371) |     | Mali<br>(N=10,519) |    | Pakistan<br>(N=12,364) |     | Rwanda<br>(N=14,634) |     | South Africa<br>(N=8,514) |     | Uganda<br>(N=18,506) |     |
|------------------------|---------------------|-----|--------------------|----|------------------------|-----|----------------------|-----|---------------------------|-----|----------------------|-----|
|                        | Per cent            | n   | Per cent           | n  | Per cent               | n   | Per cent             | n   | Per cent                  | n   | Per cent             | n   |
| <b>Age</b>             |                     |     |                    |    |                        |     |                      |     |                           |     |                      |     |
| 15–24                  | 1.06                | 64  | 0.57               | 23 | 1.35                   | 34  | 2.10                 | 119 | 1.53                      | 43  | 1.39                 | 113 |
| 25–34                  | 1.11                | 47  | 0.84               | 30 | 2.62                   | 130 | 3.02                 | 127 | 2.08                      | 58  | 2.19                 | 123 |
| 35–44                  | 1.83                | 53  | 1.70               | 39 | 6.16                   | 222 | 4.86                 | 173 | 4.25                      | 86  | 4.30                 | 155 |
| 45–49                  | 3.79                | 44  | 2.57               | 16 | 12.12                  | 159 | 8.70                 | 105 | 6.25                      | 55  | 6.54                 | 79  |
| <b>Education</b>       |                     |     |                    |    |                        |     |                      |     |                           |     |                      |     |
| No education           | 2.72                | 52  | 1.00               | 69 | 5.12                   | 311 | 6.37                 | 88  | 7.41                      | 12  | 4.81                 | 86  |
| Primary                | 1.39                | 60  | 1.41               | 20 | 5.08                   | 103 | 3.62                 | 309 | 4.97                      | 38  | 2.84                 | 302 |
| Secondary/Higher       | 1.18                | 96  | 0.84               | 19 | 3.05                   | 130 | 2.69                 | 127 | 2.52                      | 191 | 1.34                 | 82  |
| <b>Wealth quintile</b> |                     |     |                    |    |                        |     |                      |     |                           |     |                      |     |
| Poorest                | 1.29                | 28  | 1.12               | 21 | 3.49                   | 79  | 4.63                 | 127 | 3.54                      | 58  | 1.96                 | 64  |
| Poorer                 | 1.32                | 32  | 0.95               | 19 | 4.71                   | 114 | 3.57                 | 99  | 3.16                      | 54  | 3.31                 | 112 |
| Middle                 | 1.42                | 39  | 0.85               | 17 | 5.40                   | 135 | 3.22                 | 89  | 2.52                      | 45  | 3.48                 | 120 |
| Richer                 | 1.71                | 58  | 1.34               | 30 | 5.45                   | 141 | 3.33                 | 99  | 3.04                      | 54  | 2.79                 | 103 |
| Richest                | 1.41                | 51  | 0.87               | 22 | 2.90                   | 75  | 3.24                 | 111 | 1.91                      | 30  | 1.50                 | 71  |
| <b>Residency</b>       |                     |     |                    |    |                        |     |                      |     |                           |     |                      |     |
| Urban                  | 1.64                | 110 | 1.24               | 34 | 4.60                   | 209 | 3.44                 | 100 | 2.71                      | 155 | 2.02                 | 100 |
| Rural                  | 1.28                | 98  | 0.95               | 74 | 4.29                   | 335 | 3.61                 | 424 | 3.11                      | 87  | 2.72                 | 370 |
| <b>Marital status</b>  |                     |     |                    |    |                        |     |                      |     |                           |     |                      |     |
| Never in union         | 1.19                | 69  | 1.22               | 21 | 0.00                   | 0   | 2.77                 | 164 | 2.47                      | 123 | 1.89                 | 90  |
| Currently in union     | 1.47                | 109 | 0.91               | 78 | 4.15                   | 491 | 3.61                 | 267 | 3.25                      | 99  | 2.61                 | 293 |
| Formerly in union      | 2.64                | 30  | 3.24               | 9  | 10.11                  | 54  | 7.04                 | 93  | 4.11                      | 19  | 3.47                 | 87  |

An attempt was made to see if Table 3 varies by types of disability. For most disabilities, this was not possible due the small number of cases and the resulting lack of significance of the percentages. However, Table 4 shows the results for cognitive/intellectual disabilities. Almost all the percentages are statistically significant, except the case of Mali. Two reasons for reproducing this table are that: (1) a disproportionately large number of studies have focused on this particular category, according to the literature review in section 4; and (2) it the category with the largest number of significant relationships with IPV, as will be seen at the end of this study. The differences are not large enough to lead to fundamentally different conclusions about the relationship of disability with various social factors.

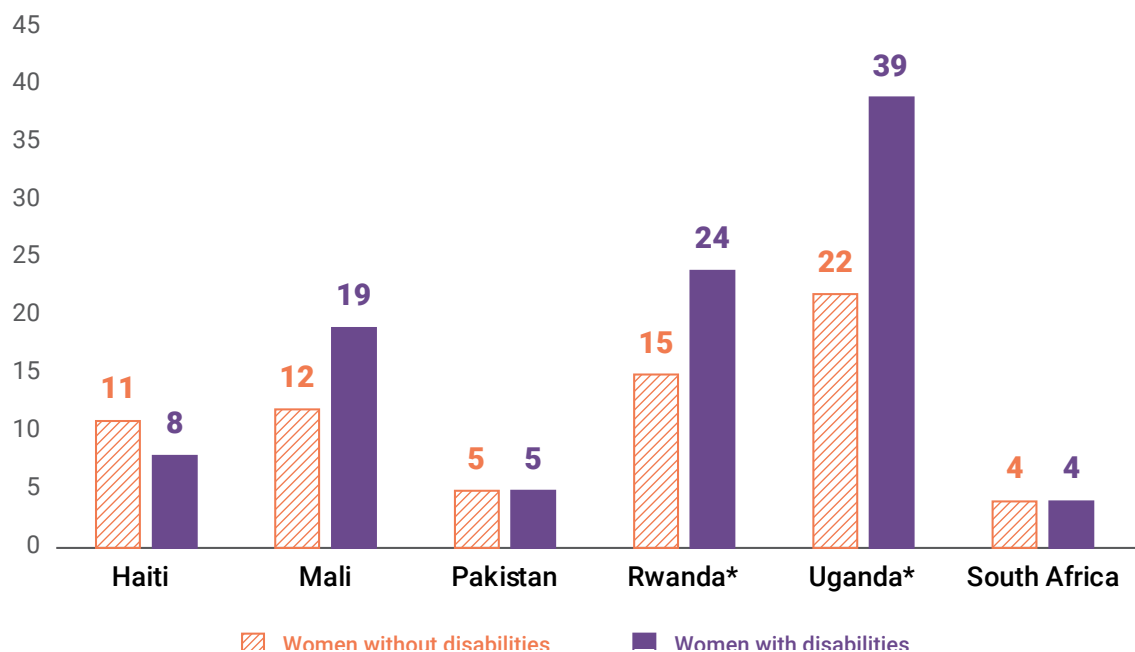
**Table 4: Prevalence of cognitive/intellectual disability by basic demographic and socioeconomic characteristics in each country (15–49 age group) for the total sample**

| Population groups      | Haiti (N=14,371) |    | Mali (N=10,519) |    | Pakistan (N=12,364) |    | Rwanda (N=14,634) |    | South Africa (N=8,514) |    | Uganda (N=18,506) |     |
|------------------------|------------------|----|-----------------|----|---------------------|----|-------------------|----|------------------------|----|-------------------|-----|
|                        | Per cent         | n  | Per cent        | n  | Per cent            | n  | Per cent          | n  | Per cent               | n  | Per cent          | n   |
| <b>Age</b>             |                  |    |                 |    |                     |    |                   |    |                        |    |                   |     |
| 15–24                  | 0.46             | 28 | (0.06)          | 3  | (0.09)              | 2  | 0.52              | 29 | 0.40                   | 11 | 0.74              | 60  |
| 25–34                  | 0.45             | 19 | (0.08)          | 3  | 0.52                | 26 | 0.54              | 23 | 0.45                   | 12 | 1.22              | 68  |
| 35–44                  | 0.34             | 10 | (0.17)          | 4  | 1.07                | 39 | 0.92              | 33 | 0.78                   | 16 | 2.33              | 84  |
| 45–49                  | (0.37)           | 4  | (0.47)          | 3  | 1.26                | 17 | 1.96              | 24 | 1.11                   | 10 | 3.59              | 43  |
| <b>Education</b>       |                  |    |                 |    |                     |    |                   |    |                        |    |                   |     |
| No education           | 0.67             | 13 | 0.14            | 9  | 0.77                | 47 | 2.29              | 32 | 2.69                   | 5  | 2.72              | 49  |
| Primary                | 0.44             | 19 | (0)             | 0  | 0.73                | 15 | 0.77              | 65 | 1.42                   | 11 | 1.59              | 169 |
| Secondary/<br>Higher   | 0.36             | 29 | (0.11)          | 2  | 0.52                | 22 | 0.24              | 11 | 0.45                   | 34 | 0.63              | 38  |
| <b>Wealth quintile</b> |                  |    |                 |    |                     |    |                   |    |                        |    |                   |     |
| Poorest                | 0.37             | 8  | (0.09)          | 2  | 0.61                | 14 | 1.07              | 29 | 0.77                   | 13 | 1.09              | 35  |
| Poorer                 | 0.20             | 5  | (0.10)          | 2  | 0.89                | 22 | 1.08              | 30 | 0.77                   | 13 | 1.98              | 67  |
| Middle                 | 0.50             | 14 | (0.16)          | 3  | 0.97                | 24 | 0.61              | 17 | 0.63                   | 11 | 1.94              | 67  |
| Richer                 | 0.45             | 15 | (0.12)          | 3  | 0.54                | 14 | 0.76              | 22 | 0.55                   | 10 | 1.49              | 55  |
| Richest                | 0.52             | 19 | (0.10)          | 2  | 0.38                | 10 | 0.28              | 10 | (0.15)                 | 2  | 0.65              | 31  |
| <b>Residency</b>       |                  |    |                 |    |                     |    |                   |    |                        |    |                   |     |
| Urban                  | 0.55             | 37 | (0.19)          | 5  | 0.82                | 37 | 0.41              | 12 | 0.45                   | 26 | 1.05              | 52  |
| Rural                  | 0.31             | 24 | 0.09            | 7  | 0.59                | 46 | 0.82              | 96 | 0.85                   | 23 | 1.50              | 204 |
| <b>Marital status</b>  |                  |    |                 |    |                     |    |                   |    |                        |    |                   |     |
| Never in union         | 0.51             | 30 | (0.10)          | 2  | 0                   | 0  | 0.64              | 38 | 0.49                   | 24 | 0.80              | 38  |
| Currently in union     | 0.35             | 26 | 0.12            | 10 | 0.65                | 77 | 0.64              | 47 | 0.64                   | 20 | 1.60              | 180 |
| Formerly in union      | (0.46)           | 5  | (0.21)          | 1  | (1.27)              | 7  | 1.75              | 23 | 1.11                   | 5  | 1.51              | 38  |

## Sexual violence

It is observed that women with disabilities are more likely to be victims of sexual violence than their peers without disabilities. The difference is especially prominent in Uganda, where 39 per cent of women with disabilities reported having been victims of sexual violence versus 22 per cent of women without disabilities (Figure 3). Uganda is followed by Rwanda (24 versus 15 per cent) where the difference is also significant. The difference is less obvious in Mali (19 versus 12 per cent). In Pakistan and South Africa no difference by disability status was reported. The opposite is observed in Haiti where 8 per cent of women with disabilities compared with 11 per cent of women without disabilities reported sexual violence.

**Figure 3: Percentage of women who experienced sexual violence, by disability status in six countries**

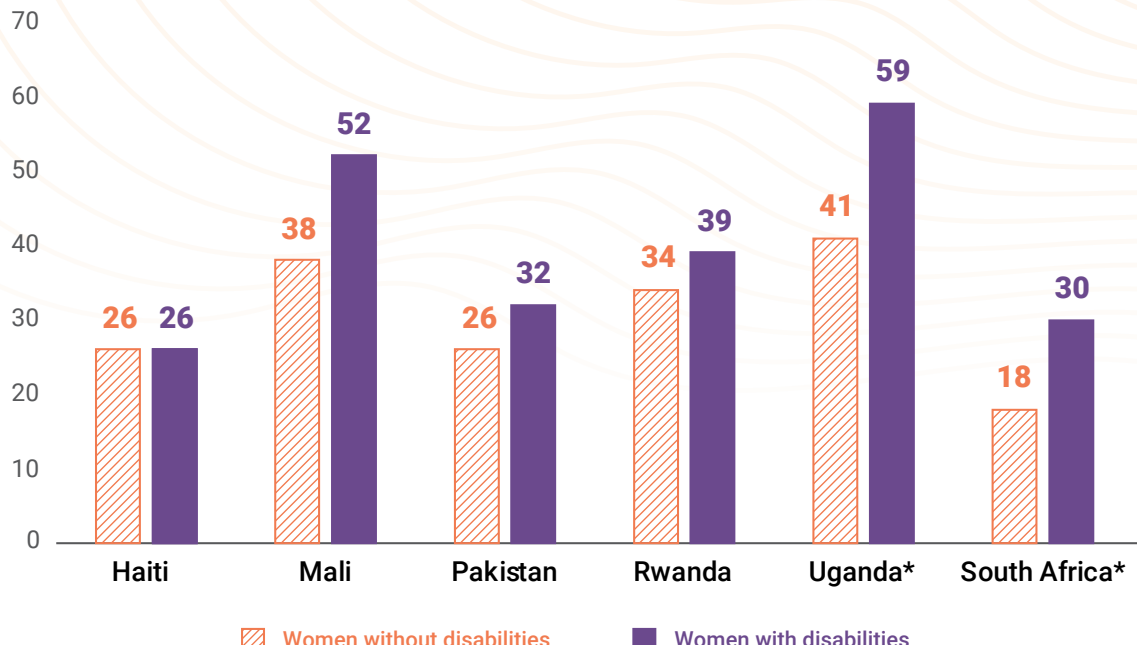


An asterisk (\*) indicates that the difference between women with and without disabilities are statistically significant at 5% level.

## Emotional violence

Figure 4 demonstrates that in the majority of countries subject to this study, women with disabilities are more likely to be victims of emotional violence than their peers without disabilities. In Uganda, 59 per cent of women with disabilities reported emotional violence versus 41 per cent of women without disabilities. The difference by disability status was also observed in South Africa (30 versus 18 per cent). Less difference was observed in Mali, where 52 per cent women with disabilities reported this type of violence versus 38 per cent of women without disabilities, followed by Rwanda (39 versus 34 per cent), Pakistan (32 versus 26 per cent).

**Figure 4: Percentage of women who experienced emotional violence, by disability status in six countries**

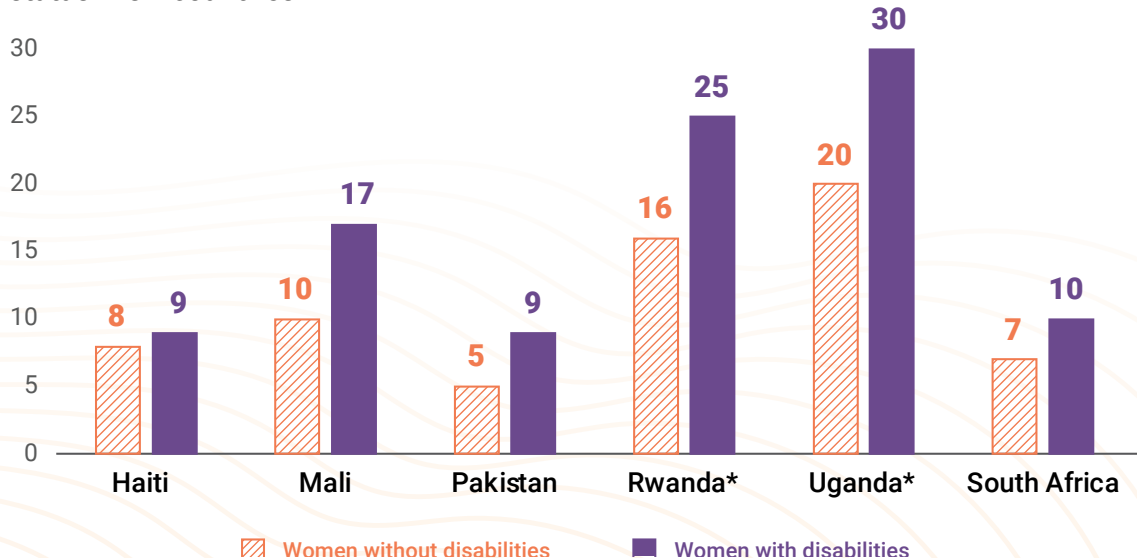


An asterisk (\*) indicates that the difference between women with and without disabilities is statistically significant at 5% level

## Severe physical violence

It is observed that in all countries women with disabilities are more likely to be victims of physical violence than their peers without disabilities, with Uganda and Rwanda demonstrating difference by disability status at a significant level (Figure 5). Uganda shows the biggest difference with 30 per cent of women with disabilities reporting severe physical violence versus 20 per cent of women without disabilities. Rwanda follows with 25 per cent of women with disabilities reporting this violence versus 16 per cent of women without disabilities. Results from Mali reveal that 17 per cent of women with disabilities report physical violence versus 10 per cent of women without disabilities followed by Pakistan (9 versus 5 per cent), South Africa (10 versus 7 per cent) and Haiti (9 versus 8 per cent). The reporting on severe physical violence is at a similar level.

**Figure 5: Percentage of women who experienced severe physical violence, by disability status in six countries**

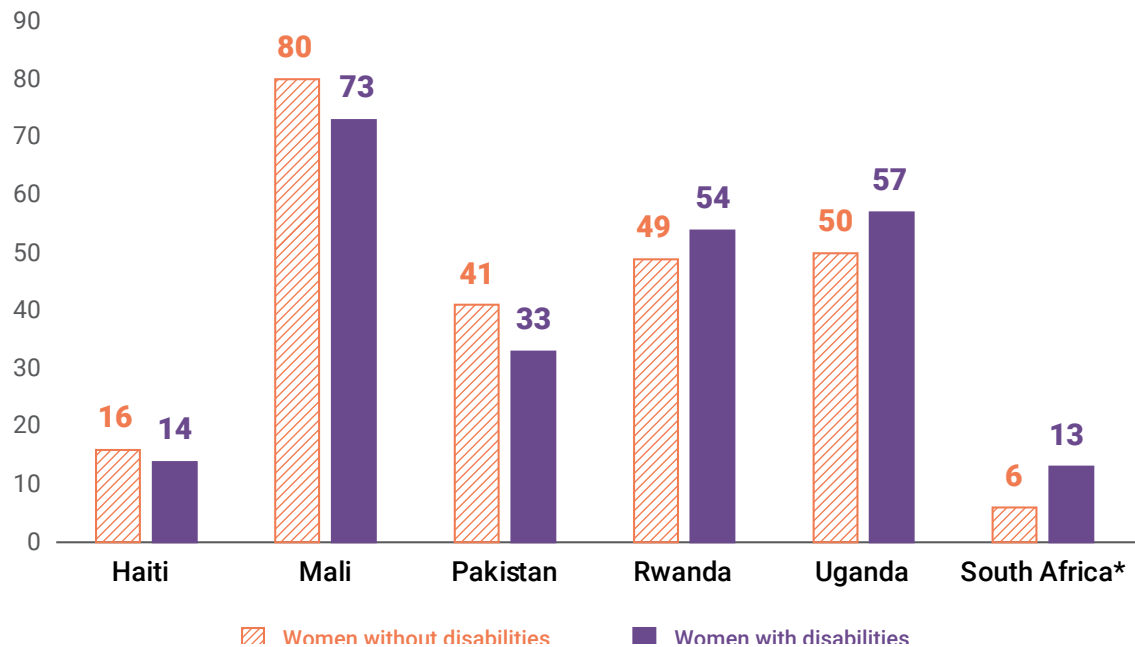


An asterisk (\*) indicates that the difference between women with and without disabilities are statistically significant at 5% level

## Acceptance of violence

The results show that in Rwanda, South Africa and Uganda, the proportion of women with disabilities who accept violence is higher than the one of their peers without disabilities, although there is significant difference by disability status only in South Africa (Figure 6). For example, in Uganda, 57 per cent of women with disabilities who answered the survey reported accepting violence compared with 50 per cent of women without disabilities. Surprisingly, three countries show an opposite trend. Haiti, Mali and Pakistan having a higher proportion of women without disabilities who accept violence than that of women with disabilities. For instance, in Pakistan, 41 per cent of women without disabilities perceive violence as legitimate compared with 33 per cent of women without disabilities.

**Figure 6: Percentage of women who accept violence, by disability status in six countries**



An asterisk (\*) indicates that the difference between women with and without disabilities are statistically significant at 5% level

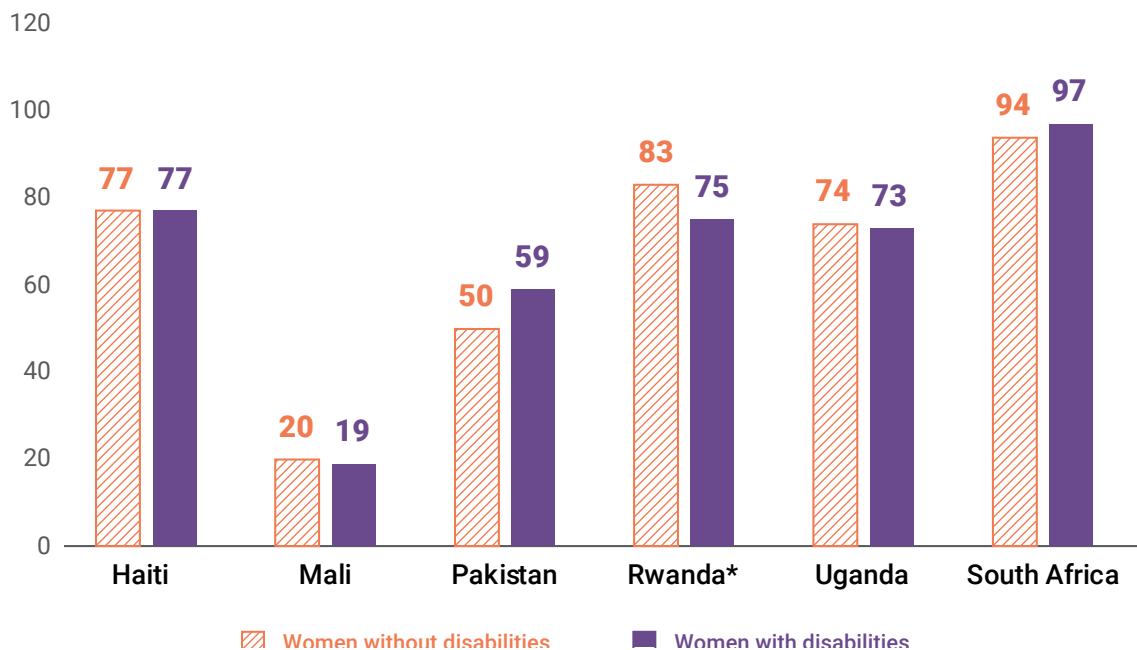
## My body, my choice: bodily autonomy

The differences between women with and without disabilities are not significant in all six study countries (Figure 7), though stark differences exist between countries. The proportion of women with autonomy in **decision-making regarding health care** ranges from 19 per cent in Mali to 97 per cent in South Africa for women with disabilities, and from 20 per cent in Mali to 94 per cent in South Africa for women without disabilities. In Haiti, Mali, Rwanda and Uganda, women with disabilities have slightly lower levels of bodily autonomy regarding health care than women without disabilities. Rwanda is the only country where this difference reaches the level of statistical significance.

The proportion of women with autonomy in **decision-making regarding contraceptive** use ranges from 61 per cent for women with disabilities in Mali to 97 per cent in Uganda compared with a range from 77 per cent in Mali to 97 per cent in Rwanda for women without disabilities. In Haiti, Mali, Pakistan and Rwanda, a slightly lower proportion of women with disabilities have decision-making autonomy regarding use of contraception than women without disabilities although the difference is not statistically significant. In Uganda and South Africa, women with disabilities have slightly more reproductive autonomy with regard to contraceptive use than women without disabilities (Figure 8).

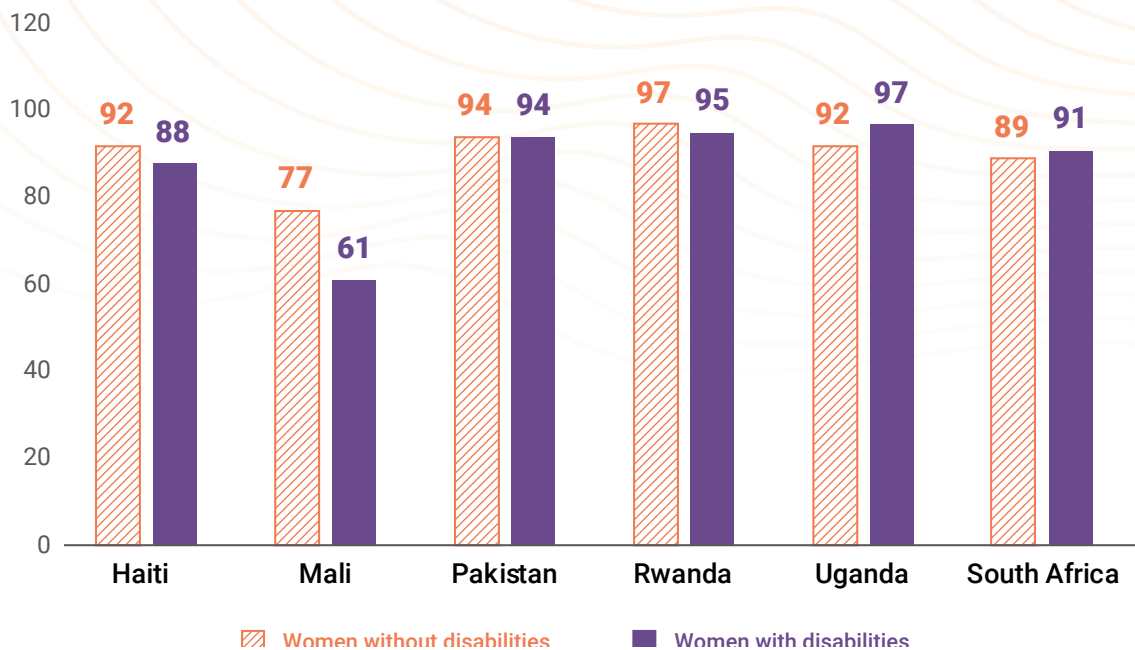
When it comes to **decision-making regarding sexual relations**, the proportion of women who can say “NO” to intercourse with their husband or partner, ranges from 19 per cent in Mali to 83 per cent in Uganda for women with disabilities, compared with a range from 26 per cent in Mali to 86 per cent in Uganda for women without disabilities. In five of the six countries, decision-making autonomy regarding sexual relations was lower for women with disabilities compared with those without disabilities, although the differences were not significant (Figure 9).

**Figure 7: Proportion of women who make their own decisions on health care by disability status and country**

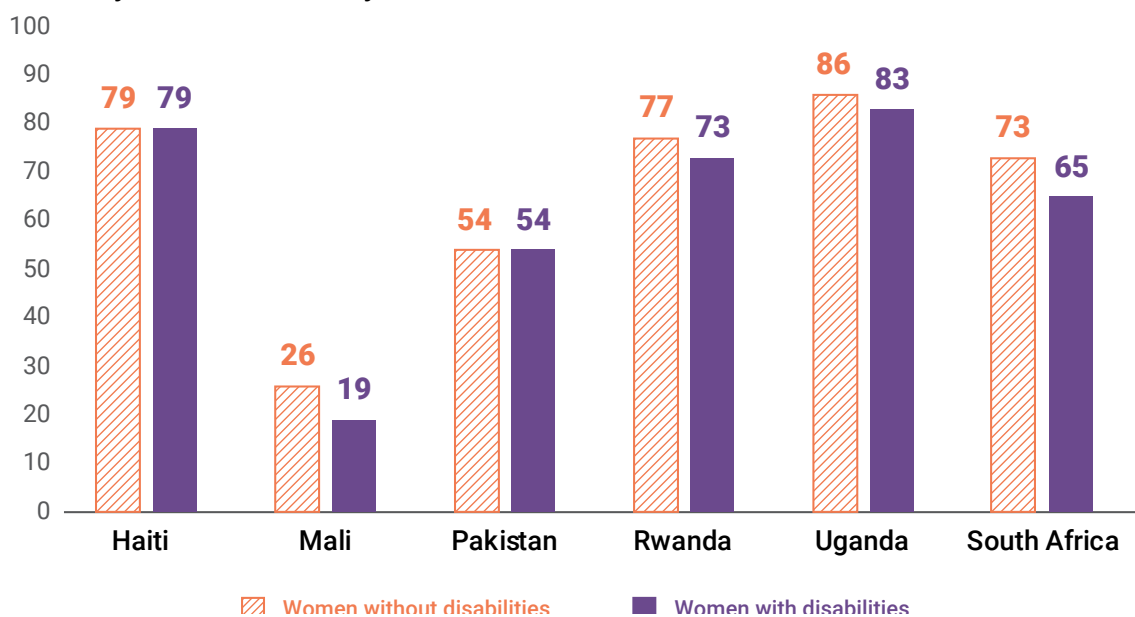


An asterisk (\*) indicates that the difference between women with and without disabilities are statistically significant at 5% level

**Figure 8: Proportion of women who make their own decisions on contraception usage by disability status and country**



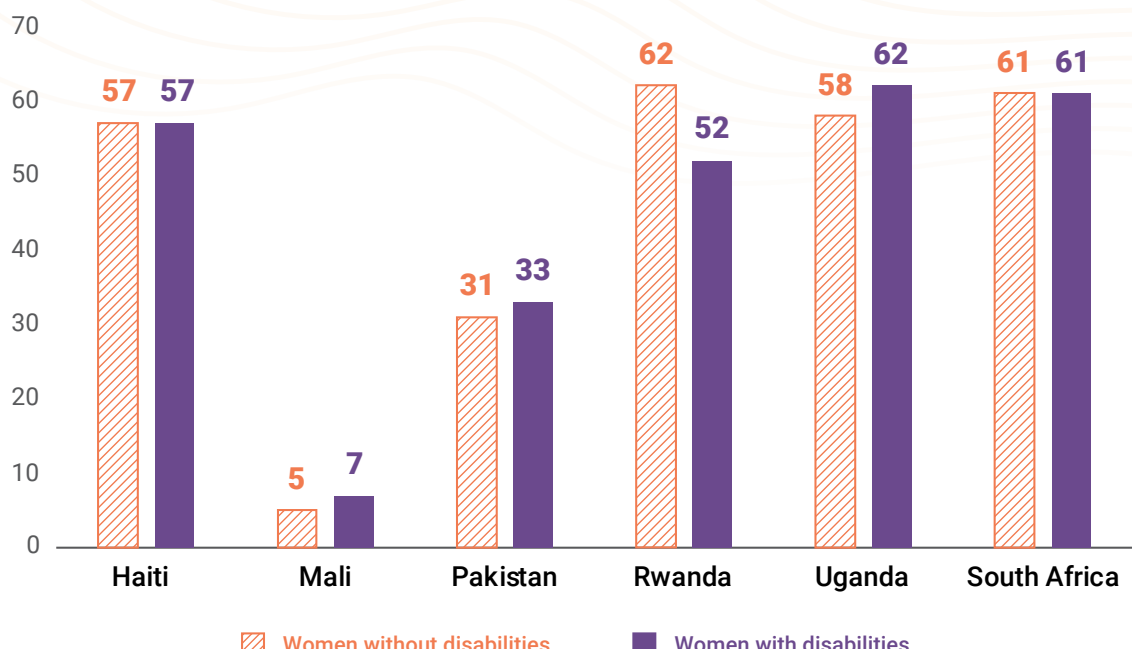
**Figure 9: Proportion of women who make their own decisions on sexual relations by disability status and country**



The proportion of women of reproductive age who are able to make autonomous decisions in all three areas: health care, contraception and saying no to sex, and thus can exercise bodily autonomy, ranges from 5 per cent in Mali to 62 per cent in Uganda for women without disabilities compared with 7 per cent in Mali to 62 per cent in Uganda for women with disabilities (Figure 10). Only in Rwanda do women with disabilities have less bodily autonomy than women without disabilities (52 versus 62 per cent). As in other countries, results are similar to those of women without disabilities. Among women with

disabilities, there are stark contrasts between countries in bodily autonomy with variation between countries ranging from 5 per cent in Pakistan to 62 per cent in Uganda.

**Figure 10: Proportion of women aged 15–49 years who are empowered to exercise bodily autonomy, i.e. women who make their own informed decisions regarding sexual relations, contraceptive use and reproductive health care, by disability status and country**



## Multiple regression results based on the pooled sample of all six countries

The samples of the six countries were pooled and an independent variable was included to identify each country. This was done to increase the power of the statistical tests and include a broader range of simultaneous independent variables. The results are shown in Tables 5 and 6. Autonomy in decisions about contraceptive use was not included as a dependent variable because it had insufficient variability to allow a multivariate analysis.

The explanatory variables with the highest levels of significance are geographic ones: country and rural or urban area of residence. Age is the third most significant factor (in the sense of having a low p-value). For most outcome variables the odds of experiencing IPV are higher for women over age 25 than for women aged 15–24. In the case of violence, this is understandable as the probability that a woman will ever have experienced violence increases with age. The exception is acceptance of violence, which is lower for women over age 25, possibly as a result of the higher probability of actually having experienced some form of violence. This interpretation does not apply to the bodily autonomy variables, which also show a higher value for ages over 25. This may be due to greater consciousness of the issues as women grow older and go through the experience of pregnancy and childbirth.



The education and wealth factors are mostly significant. In the case of education, there is a clear tendency for women with at least secondary schooling to have experienced less violence and have greater bodily autonomy. The education factor is particularly relevant because of its association with disability.

Women with disabilities are more likely not to have concluded secondary education (see Table 3), which means that some of the association between disability, experience of violence and bodily autonomy passes through education, as women with less education tend to have less favourable outcomes, regardless of their disability status. For the wealth index, there is a clear pattern of lower experience and acceptance of violence as women belong to a higher wealth quintile. Women with a higher wealth index are also more likely to make their own decisions regarding sexual relations and to have bodily autonomy in general. With respect to health care decisions, however, there is no clear pattern and none of the coefficients are statistically significant. The relationship with marital status could only be assessed in the case of IPV. It shows that women who were formerly in a union have a higher probability of having experienced all types of violence. This conclusion coincides with what was found earlier in this study. Women formerly in unions also tend to be more accepting of violence, but this relationship does not reach statistical significance.

Most importantly, there is the question of the association between disability, violence and bodily autonomy, corrected for the effect of the other intervening factors. The most clear-cut associations are those between cognitive disabilities and violence.



- ▶ Women with cognitive disabilities are at a higher risk of having experienced sexual or emotional violence and to accept violence. They are also somewhat more likely to have experienced severe physical violence, but this relationship is not statistically significant.
- ▶ Women with a self-care disability are less likely to have experienced sexual violence. This is somewhat unexpected, but the relationship is statistically significant. More in line with expectations, women with communication disabilities have a much higher probability of having experienced emotional violence.
- ▶ Women with a vision disability are more likely to have experienced severe physical violence. Hearing or mobility disabilities are not ostensibly associated with any significant negative effects regarding the experience or acceptance of violence or with bodily autonomy. In fact, the coefficients in Tables 5 and 6 suggest an advantage of women with a hearing disability over those without it.

**Table 5: Multivariate regression of experience of violence on disability status, based on the pooled sample of all six countries**

|                            |                          | Experienced any sexual violence |         | Experienced any emotional violence |         | Experienced severe physical violence |         | Accepts violence |         |
|----------------------------|--------------------------|---------------------------------|---------|------------------------------------|---------|--------------------------------------|---------|------------------|---------|
|                            |                          | OR                              | p-value | OR                                 | p-value | OR                                   | p-value | OR               | p-value |
| <b>Country</b>             | Haiti                    | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | Mali                     | 1.24                            | 0.09    | 1.89                               | 0.00    | 1.48                                 | 0.01    | 15.89            | 0.00    |
|                            | Pakistan                 | 0.46                            | 0.00    | 1.06                               | 0.52    | 0.79                                 | 0.11    | 3.14             | 0.00    |
|                            | Rwanda                   | 1.37                            | 0.00    | 1.40                               | 0.00    | 2.31                                 | 0.00    | 4.36             | 0.00    |
|                            | South Africa             | 0.37                            | 0.00    | 0.64                               | 0.00    | 1.20                                 | 0.18    | 0.44             | 0.00    |
|                            | Uganda                   | 2.18                            | 0.00    | 1.92                               | 0.00    | 3.12                                 | 0.00    | 4.51             | 0.00    |
| <b>Type of disability*</b> | Vision disability        | 0.88                            | 0.69    | 1.37                               | 0.18    | 1.78                                 | 0.04    | 0.83             | 0.43    |
|                            | Hearing disability       | 0.27                            | 0.17    | 0.56                               | 0.17    | 0.19                                 | 0.09    | 0.98             | 0.95    |
|                            | Communication disability | 2.24                            | 0.22    | 6.51                               | 0.04    | 1.88                                 | 0.35    | 0.63             | 0.50    |
|                            | Cognitive disability     | 2.75                            | 0.00    | 1.64                               | 0.01    | 1.27                                 | 0.35    | 1.47             | 0.04    |
|                            | Mobility disability      | 1.37                            | 0.20    | 1.18                               | 0.33    | 1.40                                 | 0.14    | 0.75             | 0.12    |
|                            | Self-care disability     | 0.11                            | 0.04    | 1.11                               | 0.87    | 0.46                                 | 0.43    | 2.27             | 0.24    |
| <b>Age group</b>           | 15–24                    | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | 25–34                    | 1.16                            | 0.03    | 1.32                               | 0.00    | 1.22                                 | 0.01    | 0.78             | 0.00    |
|                            | 35–44                    | 1.03                            | 0.67    | 1.24                               | 0.00    | 1.20                                 | 0.02    | 0.71             | 0.00    |
|                            | 45–49                    | 0.90                            | 0.33    | 1.20                               | 0.02    | 1.29                                 | 0.02    | 0.60             | 0.00    |
| <b>Education</b>           | No education             | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | Primary                  | 1.31                            | 0.00    | 1.05                               | 0.41    | 1.03                                 | 0.70    | 0.81             | 0.00    |
|                            | Secondary/higher         | 0.91                            | 0.36    | 0.77                               | 0.00    | 0.65                                 | 0.00    | 0.44             | 0.00    |
| <b>Wealth index</b>        | Poorest                  | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | Poorer                   | 1.10                            | 0.19    | 0.96                               | 0.46    | 0.81                                 | 0.00    | 0.89             | 0.04    |
|                            | Middle                   | 1.03                            | 0.70    | 0.94                               | 0.34    | 0.74                                 | 0.00    | 0.79             | 0.00    |
|                            | Richer                   | 1.02                            | 0.78    | 0.87                               | 0.04    | 0.59                                 | 0.00    | 0.68             | 0.00    |
|                            | Richest                  | 0.69                            | 0.00    | 0.65                               | 0.00    | 0.39                                 | 0.00    | 0.59             | 0.00    |
| <b>Marital status</b>      | Never in union           | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | Currently in union       | 1.33                            | 0.28    | 0.81                               | 0.04    | 1.07                                 | 0.67    | 0.99             | 0.92    |
|                            | Formerly in union        | 2.52                            | 0.00    | 1.61                               | 0.00    | 2.77                                 | 0.00    | 1.12             | 0.18    |
| <b>Residence</b>           | Urban                    | 1.00                            |         | 1.00                               |         | 1.00                                 |         | 1.00             |         |
|                            | Rural                    | 0.84                            | 0.04    | 0.84                               | 0.00    | 0.68                                 | 0.00    | 1.22             | 0.00    |
| <b>Constant</b>            |                          | 0.09                            | 0.00    | 0.45                               | 0.00    | 0.11                                 | 0.00    | 0.44             | 0.00    |

\* These coefficients express by how much the probability of the dependent variable (experience or acceptance of violence) changes if the woman has a particular disability. If the coefficient is larger than 1, it increases the probability; if it is smaller than 1, it diminishes the probability. If the woman has more than one disability, the effects are cumulative. The overall reference for comparison is a Haitian woman without disabilities aged 15–24 years, with no education, from the poorest wealth quintile, living in an urban area. Therefore, a woman without any disability would have a score of 1 (i.e. no effect) on the type of disability dimension.

In the case of bodily autonomy, this UNFPA study found an unexpected pattern of higher bodily autonomy for women with disabilities. However, none of the coefficients are statistically significant, so not too much importance should be attributed to this finding, curious as it is. This suggests the importance of differentiating between different categories of disability as not all of them have the same effects. In accordance with the literature review, the most problematic categories are cognitive/intellectual disabilities and, to a lesser extent, communication or vision disabilities.

**Table 6: Multivariate regression of bodily autonomy on disability status, based on the pooled sample of all six countries**

|                            |                          | Makes own decisions on health care |         | Makes own decisions on sexual relations |         | Has bodily autonomy |         |
|----------------------------|--------------------------|------------------------------------|---------|---|---------|---------------------|---------|
|                            |                          | OR                                 | p-value | OR                                      | p-value | OR                  | p-value |
| <b>Country</b>             | Haiti                    | 1.00                               |         | 1.00                                    |         | 1.00                |         |
|                            | Mali                     | 0.09                               | 0.00    | 0.12                                    | 0.00    | 0.05                | 0.00    |
|                            | Pakistan                 | 0.34                               | 0.00    | 0.40                                    | 0.00    | 0.39                | 0.00    |
|                            | Rwanda                   | 1.47                               | 0.00    | 0.97                                    | 0.73    | 1.26                | 0.01    |
|                            | South Africa             | 4.35                               | 0.00    | 0.58                                    | 0.00    | 0.93                | 0.43    |
|                            | Uganda                   | 1.03                               | 0.72    | 1.86                                    | 0.00    | 1.21                | 0.01    |
| <b>Type of disability*</b> | Vision disability        | 1.13                               | 0.64    | 0.78                                    | 0.32    | 0.84                | 0.45    |
|                            | Hearing disability       | 1.26                               | 0.67    | 1.89                                    | 0.26    | 2.32                | 0.12    |
|                            | Communication disability | 4.93                               | 0.22    | 4.78                                    | 0.27    | 6.86                | 0.18    |
|                            | Cognitive disability     | 0.78                               | 0.39    | 1.04                                    | 0.88    | 1.09                | 0.74    |
|                            | Mobility disability      | 1.08                               | 0.76    | 1.17                                    | 0.49    | 1.09                | 0.67    |
|                            | Self-care disability     | 1.60                               | 0.47    | 1.16                                    | 0.82    | 1.42                | 0.56    |
| <b>Age group</b>           | 15–24                    | 1.00                               |         | 1.00                                    |         | 1.00                |         |
|                            | 25–34                    | 1.68                               | 0.00    | 1.13                                    | 0.07    | 1.54                | 0.00    |
|                            | 35–44                    | 2.32                               | 0.00    | 1.12                                    | 0.09    | 1.78                | 0.00    |
|                            | 45–49                    | 2.19                               | 0.00    | 1.05                                    | 0.54    | 1.63                | 0.00    |
| <b>Education</b>           | No education             | 1.00                               |         | 1.00                                    |         | 1.00                |         |
|                            | Primary                  | 1.11                               | 0.12    | 1.36                                    | 0.00    | 1.29                | 0.00    |
|                            | Secondary/Higher         | 1.39                               | 0.00    | 1.91                                    | 0.00    | 1.78                | 0.00    |
| <b>Wealth index</b>        | Poorest                  | 1.00                               |         | 1.00                                    |         | 1.00                |         |
|                            | Poorer                   | 0.89                               | 0.10    | 1.03                                    | 0.68    | 0.96                | 0.56    |
|                            | Middle                   | 0.94                               | 0.40    | 1.22                                    | 0.01    | 1.02                | 0.75    |
|                            | Richer                   | 1.02                               | 0.82    | 1.33                                    | 0.00    | 1.15                | 0.10    |
|                            | Richest                  | 0.98                               | 0.83    | 1.29                                    | 0.02    | 1.22                | 0.05    |
| <b>Residence</b>           | Urban                    | 1.00                               |         | 1.00                                    |         | 1.00                |         |
|                            | Rural                    | 0.80                               | 0.00    | 0.80                                    | 0.00    | 0.82                | 0.01    |
| <b>Constant</b>            |                          | 1.84                               | 0.00    | 2.22                                    | 0.00    | 0.65                | 0.00    |



## 6. Discussion

This report tells a comprehensive story of bodily autonomy and exposure to IPV for women with disabilities across six countries. In exploring these often-overlooked aspects of sexual and reproductive health, it has uncovered some critical findings about women of reproductive age with disabilities. This study presents the following findings:



- ▶ Regardless of disability status or other explanatory factors, there are major differences between countries concerning the incidence of exposure to IPV and, to a lesser extent, regarding bodily autonomy.
- ▶ Women with disabilities across all countries are more likely to be of older age, have a lower level of education, to live in poverty, and to live in urban areas.
- ▶ In the case of IPV, the differences between women with and without disabilities found in the analysis were mostly statistically significant. In the case of bodily autonomy, they were small and often did not reach statistical significance.
- ▶ There are major differences between the impacts of different kinds of disability, with worse outcomes in the case of cognitive/intellectual and, to a lesser extent, communication or vision disabilities.
- ▶ The effects of disability on acceptance of violence are larger than on the actual experience of violence.
- ▶ When differences exist, women with disabilities are more likely to be disadvantaged when it comes to indicators on IPV and bodily autonomy, but this does not hold consistently in all countries or for all types of disabilities.

Human rights related to bodily autonomy in the context of sexuality and reproduction ensure that women with disabilities are empowered to make decisions about their reproductive and sexual lives. Bodily autonomy is a cornerstone for achieving SDG targets 3.7 and 5.6. It was somewhat surprising that the results of this study did not indicate significant differences between women with and without disabilities when it came to the component indicator on bodily autonomy. Of the three areas of measurement (decision-making on health care, contraception and saying no to sex), women with disabilities were slightly less likely to say no to sex in most of the studied countries. This corresponds with the result of this analysis related to gender-based violence on women with disabilities being more likely to be victims of sexual violence than their peers without disabilities. Consequently, there is abundant room for further progress in our understanding of IPV to inform prevention and response efforts, including access to services and information.

A possible explanation for these results may be the challenges in designing a data collection strategy for disability in the context of IPV and bodily autonomy. These two distinct areas of data collection share a relatively small intersection in conventional data collection instruments, given constraints on sample size and on the number of questions that can be asked during a survey. Due to the limitations in sample size and questionnaire content, it was not possible to consider all the control variables that might have been relevant. The observed results do not take into account the impact of different types and degrees of physical difficulties and how these interacted with the attitudinal, communication, physical and other barriers that the respondents with disabilities may have faced. How well data collectors were trained on disability and if the perception of the disability of household members was the same for the respondent of the household questionnaire and the person(s) affected remains unknown.

Moreover, the WG–SS relies on self-reporting of disability, which can be further impacted by the underlying power structures and internalized disability-related stigma. Many respondents with disabilities have little or no education, and may not fully understand why certain information is being collected. Therefore, they may be obliging, shy, in a vulnerable position, and may not have the confidence to ask questions to clarify their understanding. It remains unknown how well women with intellectual and psychosocial disabilities or those with sensory impairments have been able to participate in the surveys. Furthermore, research on women with disabilities that draws comparisons with the general population may yield misleading results, because women who have severe developmental and cognitive disabilities are underrepresented in such surveys and among women in intimate relationships.<sup>144,145</sup>

The WG–SS is a significant development in generating nuanced data on disability, yet the Washington Group questions were not designed specifically for the purpose of measuring

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144 Kwagala, Betty, Johnstone Galande, and Paul Musimami. 2019. Disability, Partner behaviors, and the risk of Intimate partner violence in Uganda: further analysis of the 2016 Demographic and Health Survey. DHS Working Paper No. 150. Rockville, Maryland, USA: ICF.

145 Sobsey, D. 2006. "Violence and Disability." Health Promotion for Persons with Intellectual/developmental Disabilities: The State of Scientific Evidence: 205-234.

psychosocial disabilities. The WG–SS Enhanced and Extended sets do so. The omission of psychosocial disabilities from the WG–SS has implications for what is known about younger women with psychosocial disabilities. The addition of a disability module of the kind implemented by DHS allows researchers to cross-tabulate various IPV indicators by disability status.

Furthermore, the sample of the DHS is not designed to deal specifically with mental health functioning and relatively rare situations such as a severe disability in women of reproductive age.<sup>146</sup> This limits the possibilities for a detailed sub-analysis of the original sample. On the other hand, for the purposes of this study, we limited our analysis to those experiencing a lot of difficulty in performing a given function or who cannot perform it at all, rather than to persons experiencing some degree of difficulty. While this is the recommended definition of disability by the Washington Group on Disability Statistics for the purpose of focusing programmes and policies, it resulted in small samples of women with disabilities. Finally, structured short-set questionnaires on disability are not designed to capture a rich picture of the population. More questions on functioning and detailed studies through mixed methods are needed to better understand these variables.

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146 Groce, N. E., & Mont, D. (2017). Counting disability: emerging consensus on the Washington Group questionnaire. *The Lancet Global Health*, 5 (7), 649-650



The ideal option would be a specific survey programme designed to measure the impact of disabilities of women in different domains of disability and different aspects of IPV and bodily autonomy. This would require sample sizes large enough to analyse sub-groups and the inclusion of specific questions to investigate issues that might be of concern to women with disabilities. Engaging persons with disabilities in the study design and data collection would also improve how well the experiences of women with disabilities are included and counted in research.

Another important issue is the large variation between countries that was noted at the beginning of this section. This finding raises intriguing questions regarding the contextual understanding of both IPV and disability and has implications for developing context-specific qualitative methodologies that could provide insight into the source of these differences across countries. Nevertheless, complementing existing studies, including qualitative studies, the findings of this analysis provide vital information on the variations in bodily autonomy and exposure to gender-based violence between women with and without disabilities across different contexts.

To reach common goals, stronger methodologies to strengthen data on disability, IPV and bodily autonomy must be developed to more fully explore the relevant impacts, as well as to avoid the pitfalls related to researching disability. Improved new data will strengthen evidence-informed policy and decision-making and accelerate the global momentum generated by ICPD+25 and the Generation Equality (Beijing+25) Forum.



## 7. Recommendations

The rights of women with disabilities are addressed by various United Nations agencies, Member States and civil society actors, including organizations of persons with disabilities. More action is needed to push back against the excluding forces that push women with disabilities to the margins of the society and threaten their freedom from violence. A continuing lack of participation by women with disabilities in many programmatic planning, implementation, monitoring and evaluation efforts remains a specific cause for concern. To address these challenges, UNFPA is committed to mainstreaming disability inclusion across its operations and programmes, while also implementing targeted actions for disability inclusion. Furthermore, UNFPA is enhancing its positioning and advocacy on disability inclusion within the ICPD mandate, and establishing innovative mechanisms to ensure meaningful engagement and leadership for women with disabilities and their representative organizations in decision-making processes. Three main types of actions should be considered by a broad range of actors to ensure that women with disabilities in all their diversity are protected against violence and realize greater autonomy in decision-making:



### RECOMMENDATION 1:

#### Advocate for an enabling legal, policy and social environment for autonomous decision-making

The CRPD emphasizes the importance of legal capacity: “All women with disabilities must be able to exercise their legal capacity by taking their own decisions, with support when desired, with regard to medical and/or therapeutic treatment, including by taking their own decisions on retaining their fertility and reproductive autonomy...”<sup>147</sup> States, civil society

<sup>147</sup> United Nations Committee on the Rights of Persons with Disabilities, 2016. “General Comment No. 3 (2016) on Women and Girls with Disabilities.” CRPD/C/GC/3.



organizations and communities must take measures to protect the bodily autonomy of those living with disabilities by strengthening understanding and implementation of the following key concepts related to autonomous decision-making regarding sexual and reproductive health and rights in laws, policies and services:

- ▶ Equal Recognition Before the Law is the right of all people everywhere under human rights law.<sup>148,149</sup> Article 12 of the CRPD expressly provides that States must realize this right for persons with disabilities and explains what this right looks like for persons with disabilities.<sup>150</sup> Understanding the right of persons with disabilities to equal recognition before the law is necessary so service providers can ensure that they do not participate in violating such rights.
- ▶ Legal capacity is “the capacity to be both a holder of rights and an actor under the law. Legal capacity entitles a person to full protection of his or her rights by the legal system, with the power to engage in transactions and create, modify, or end legal relationships.”<sup>151,152</sup> Supported decision-making may be necessary to empower some persons with disabilities to exercise their legal rights.<sup>153</sup>
- ▶ Informed consent, according to the International Federation of Gynecology and Obstetrics (FIGO), is a process of communication between a service provider and a service recipient that results in the service recipient giving, withdrawing, or refusing permission for a procedure based on full knowledge of the procedure.<sup>154</sup> Informed consent is important because it upholds the rights, autonomy and dignity of all, including persons with disabilities.

Supported decision-making comprises various support options that give primacy to a person’s will and preferences and respect human rights norms. It should protect all rights, including those related to autonomy (e.g. right to legal capacity, right to equal recognition before the law) and rights related to freedom from abuse and ill-treatment (e.g. right to life, right to physical integrity). Supported decision-making stands in contrast to substituted decision-making models, such as guardianship, which perpetuate power imbalances, and thereby can make persons with disabilities vulnerable to gender-based violence and other forms of abuse and ill-treatment.<sup>155</sup>

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148 UNFPA (2018) Women and Young People with Disabilities - Guidelines for Providing Rights Based and Gender Responsive Services to Address GBV and SRHR, p 15

149 See Universal Declaration of Human Rights, arts. 6-7, G.A. Res. 217A, pmb., U.N. GAOR, 3d Sess., 1st plen. mtg., at 71, U.N. Doc. A/810 (Dec. 10, 1948); International Covenant on Civil and Political Rights, adopted Dec. 16, 1966, arts. 14, 16, 26, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (entered into force Mar. 23, 1976) [hereinafter ICCPR]; Convention on the Elimination of All Forms of Discrimination against Women, adopted Dec. 18, 1979, art. 15, 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).

150 CRPD Committee, General Comment No. 1 (2014) Article 12: Equality Recognition Before the Law, para. 29, U.N. Doc. CRPD/C/ GC/1 (May 19, 2014) [hereinafter CRPD Committee, General Comment No. 1].

151 UNFPA-WEI Women and Young People with Disabilities - Guidelines for Providing Rights Based and Gender Responsive Services to Address GBV and SRHR, p 16.

152 CRPD Committee, General Comment No. 1, at para. 12.

153 CRPD Committee, General Comment No. 1, at para. 29.

154 UNFPA (2018). Women and Young People with Disabilities - Guidelines for Providing Rights Based and Gender Responsive Services to Address GBV and SRHR, p 16.

155 UNFPA (2018) Women and Young People with Disabilities - Guidelines for Providing Rights-Based and Gender Responsive Services to Address GBV and SRHR, p 153.



## RECOMMENDATION 2:

Recognize the different degrees of vulnerability to IPV faced by women with different types of disability and the particular problems faced by women with cognitive/intellectual and communication disabilities.

- ▶ Promote concerted efforts to advance the sexual and reproductive health and rights of women with disabilities in line with Leaving No One Behind (LNOB), the United Nations principle that includes all groups excluded from progress, including those impacted due to their gender alone.
- ▶ Develop alternative forms of communication and information and the reinforcement of assertiveness, to ensure that women with cognitive/intellectual or communication disabilities have the means to provide or withhold their consent to sexuality and other aspects of their sexual and reproductive health and rights.
- ▶ The finding that the effects of disability on acceptance of violence are higher than those on the actual experience of violence suggests that more attention should be paid to raising awareness of this issue among women with disabilities themselves.
- ▶ Develop country-specific strategies to promote a culture of non-violence and increase the bodily autonomy of women with disabilities, taking into account the large disparities between countries in terms of acceptance of violence and exercise of bodily autonomy.



## RECOMMENDATION 3:

Develop, advocate and implement improved research methodologies for stronger data on disability and IPV.

- ▶ Strengthen financing for data efforts to monitor, evaluate and develop levels of GBV and services to attend to the survivors of IPV.
- ▶ Conduct empirical research on IPV against women with disabilities, with an emphasis on low- and middle-income countries, including more intersectional data, such as IPV among women from ethnic and other minorities.
- ▶ Strengthen the use of disability measures to meet different policy objectives and develop new measures as needed:
  - Develop a general disability measure, including psychosocial disability, to monitor the level of functioning in a population and formulate disability-inclusive policies.
  - Develop a measure of severe disability to identify persons with high service needs for the purpose of health and social policy design.
  - Develop a more operational definition of bodily autonomy that facilitates its measurement in surveys such as the DHS.
  - Include persons with disabilities, especially women, in the design and data collection of survey methodologies.
  - Adapt research questions to the actual situation in each country, especially those relating to the distribution and use of services and support. This need was demonstrated in the present research, which found that access to and use of services, especially public services, differs greatly among countries.

# Annexes

## Annex I: Summary of advantages and limitations of data collection instruments for disability and IPV and bodily autonomy by design and content

This table is based on the Disability Statistics Resource Guide (2019) developed for UNFPA by Ralph Hakkert.

|  | Advantages   | Limitations   | Methodological considerations   |
|--|--|---|---|
| <b>Census</b>  | <ul style="list-style-type: none"> <li>Covers the entire population so that even rare health conditions can be captured in the correct proportions.</li> <li>Provides an idea about the differences between people with and without particular disabilities in each relevant sub-population.</li> <li>Provides extremely useful descriptive data on differences between individuals with and without disabilities.</li> <li>Provides a good way to identify persons with severe disabilities.</li> </ul> | <ul style="list-style-type: none"> <li>General data collection instrument that cannot go into any detail on issues of particular interest.</li> <li>Census data may not be reliable when they refer to very personal or sensitive information.</li> <li>Limited number of questions on any particular subject.</li> <li>Does not provide much insight on disability and how it affects particular aspects of an individual's everyday life.</li> <li>The general census question identifies typically fewer persons with disabilities than in national disability surveys.</li> <li>Does not identify well individuals with moderate disabilities and works very poorly for counting individuals with mild disabilities.</li> </ul> | <ul style="list-style-type: none"> <li>If the census contains disability screening questions, this strategy can be used to optimize the sampling of the disability-specific surveys.</li> <li>Confidentiality issues with respect to the use of census data may be an obstacle, depending on the census legislation in particular countries.</li> </ul> |
| <b>Special disability modules in surveys carried out for other purposes (DHS, World Health Survey, MICS, etc.)</b> | <ul style="list-style-type: none"> <li>Possibility to examine disability as an outcome of interactions between a person with a health condition and various environmental and personal factors.</li> <li>Provides a more complete understanding of the lived experience of persons with disabilities and provides a better approximation of its true size.</li> </ul>  | <ul style="list-style-type: none"> <li>Sampling variability and the difficulty of sub-dividing the population into small categories in order to study particular relationships.</li> <li>Sampling of such surveys is not specifically oriented towards the investigation of disability and hence the number of persons with disabilities that are sampled in surveys of this kind is typically small.</li> <li>Amount of detail that can be provided is limited.</li> </ul>   | <ul style="list-style-type: none"> <li>Cross-tabulation of disability status by standard socioeconomic characteristics is the main form of data collection in the majority of special disability modules in surveys carried out for other purposes.</li> </ul>  |

|   | Advantages  | Limitations   | Methodological considerations  |
|---|---|---|--|
| Dedicated disability surveys                    | <p>Produces more precise disability rates than census.</p> <p>Surveys specifically dedicated to collect disability data can provide a broader set of information than censuses or short disability modules inserted in other kinds of surveys about prevalence rates.</p>   | <p>Various stages are required for sampling. In special disability surveys, like in any special surveys, the first stage is to identify the target population.</p> <p>Many countries have not attempted to conduct such disability surveys because they are more costly than simply adding a few questions into a census or already existing sample surveys.</p>  | <ul style="list-style-type: none"> <li>• If conducted after a census, screening questions on disability in censuses can support the sampling of special disability surveys.</li> <li>• Case-control study design has proven useful.</li> </ul> |
| Surveys focused on service providers            | <p>Systematically collects data from caregiving institutions.</p> <p>Collects data on the preparedness of primary health care units and family planning clinics to attend to clients with disabilities.</p> <p>These surveys could include the following aspects: the training of staff to attend to persons with disabilities, presence of a psychologist to attend to patients with mental problems, ability of the staff to communicate in sign language or in simplified terminology, if necessary, adapted equipment to conduct examinations, availability of information in Braille, and accessible or universal design of the facilities.</p>  | <p>Careful considerations need that take into account the specific legal norms and regulations that are in effect in the country. If no such legislation exists in the country, there is little point in assessing if local facilities comply with it.</p> <p>DHS collects data on the most common SRH services, but not on services that typically provide support to victims of IPV.</p>  |  |
| Institutional/administrative disability data    | <p>Information collected is organized and becomes part of normal service administration procedure such as the information gathered using standard client intake forms for health, rehabilitation or social work services.</p> <p>With only minimal analysis, these data can answer basic administrative questions:<br/> How many people were supported by the service in a given time period, and what were their characteristics and support needs?<br/> What type of support was provided and received?<br/> What quantity of support (e.g. in terms of staff hours) was provided and received?<br/> From whom was the support received (e.g. in terms of details of the service agency, such as size, staff profile, and hours)?<br/> What was the cost (e.g. total, per service type, per client) of providing these services?<br/> What were the outcomes for clients?<br/> Examples of outcome questions include:<br/> Were clients satisfied with the services received? Were there increased levels of client participation in key life areas such as employment?</p> | <p>Cannot provide information about persons with disabilities who need a service or programme but do not receive it. Data about unmet need has to come from other sources.</p> <p>The definition of disability in administrative data is usually different from that used in the census as administrative data tend to be skewed towards the beneficiaries of special programmes or services, particularly those who receive benefits because of their inability to work. Women of reproductive age tend to be under-represented in these systems.</p> <p>It is usually not possible to cross-reference administrative systems regarding disability with those that deal with reports of domestic or other types of violence.</p> |  |
| Database surveys on legal and policy frameworks | <p>This allows for assessing whether an adequate legal framework exists at all.</p>   | <p>The legislation of the countries should be analysed, to verify if the conditions are fulfilled.</p>  |  |

## Annex II: DHS disability module questions

DHS Questionnaire Modules (English, French) are available at <https://dhsprogram.com/publications/publication-dhsqm-dhs-questionnaires-and-manuals.cfm>

| IF AGE 5 OR OLDER |  |   |   |                                 |  |  |
|-------------------|--|---|---|---------------------------------|--|--|
| LINE NO.          | DISABILITY   |   |   |                                 |  |  |
|                   | 26   | 27  | 28  | 29                              | 30   | 31   |
|                   | Does (NAME) wear glasses or contact lenses to help them see? | I would like to know if (NAME) has difficulty seeing even when wearing glasses or contact lenses. Would you say that (NAME) has no difficulty seeing, some difficulty, a lot of difficulty, or cannot see at all? | I would like to know if (NAME) has difficulty seeing. Would you say that (NAME) has no difficulty seeing, some difficulty, a lot of difficulty, or cannot see at all? | Does (NAME) wear a hearing aid? | I would like to know if (NAME) has difficulty hearing even when using a hearing aid. Would you say that (NAME) has no difficulty hearing, some difficulty, a lot of difficulty, or cannot hear at all? | I would like to know if (NAME) has difficulty hearing. Would you say that (NAME) has no difficulty hearing, some difficulty, a lot of difficulty, or cannot hear at all? |
|                   |  | 1 = NO DIFFICULTY SEEING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT SEE AT ALL<br>8 = DON'T KNOW   | 1 = NO DIFFICULTY SEEING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT SEE AT ALL<br>8 = DON'T KNOW   | (1)                             | (1)<br>1 = NO DIFFICULTY HEARING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT HEAR AT ALL<br>8 = DON'T KNOW   | 1 = NO DIFFICULTY HEARING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT HEAR AT ALL<br>8 = DON'T KNOW  |
| 1                 | Y N<br>1 2<br>↓<br>GO TO 28                                  | 1 2 3 4 8<br>(GO TO 29)   | 1 2 3 4 8   | Y N<br>1 2<br>↓<br>GO TO 31     | 1 2 3 4 8<br>(GO TO 32)  | 1 2 3 4 8  |

|   | 32  | 33  | 34  | 35   |
|---|---|---|---|--|
|   | I would like to know if (NAME) has difficulty communicating when using his/her usual language. Would you say that (NAME) has no difficulty understanding or being understood, some difficulty, a lot of difficulty, or cannot communicate at all? | I would like to know if (NAME) has difficulty remembering or concentrating. Would you say that (NAME) has no difficulty remembering or concentrating, some difficulty, a lot of difficulty, or cannot remember or concentrate at all? | I would like to know if (NAME) has difficulty walking or climbing steps. Would you say that (NAME) has no difficulty walking or climbing steps, some difficulty, a lot of difficulty, or cannot walk or climb steps at all? | I would like to know if (NAME) has difficulty washing all over or dressing. Would you say that (NAME) has no difficulty washing all over or dressing, some difficulty, a lot of difficulty, or cannot wash all over or dress at all? |
|   | 1 = NO DIFFICULTY COMMUNICATING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT COMMUNICATE AT ALL<br>8 = DON'T KNOW  | 1 = NO DIFFICULTY REMEMBERING/<br>CONCENTRATING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT REMEMBER/<br>CONCENTRATE AT ALL<br>8 = DON'T KNOW   | 1 = NO DIFFICULTY WALKING<br>OR CLIMBING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT WALK OR<br>CLIMB AT ALL<br>8 = DON'T KNOW  | 1 = NO DIFFICULTY WASHING<br>OR DRESSING<br>2 = SOME DIFFICULTY<br>3 = A LOT OF DIFFICULTY<br>4 = CANNOT WASH OR<br>DRESS AT ALL<br>8 = DON'T KNOW   |
| 1 | 1 2 3 4 8   | 1 2 3 4 8   | 1 2 3 4 8   | 1 2 3 4 8  |



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