

My Body, *(but not)* My Choice

Legal Capacity Violations against
Women with Intellectual Disabilities
and Women with Psychosocial Disabilities
and Recommendations for Action

Human Rights Report
2025



Acknowledgments

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A content warning: The experiences shared throughout this report speak to difficult topics that readers may find distressing, including eugenics, many forms of gender-based violence, depression, and discrimination against persons with disabilities.

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Executive Summary

The Right to Legal Capacity and its Violations

The right to legal capacity guarantees that every adult has the right to make decisions independently—or with support if they wish—and to have those decisions recognized by law and respected by others. This right is a prerequisite to enjoying many other rights,¹ and it is guaranteed in several international treaties, including the Convention on the Rights of Persons with Disabilities.

Despite that, globally, women with disabilities continue to experience violations of their right to legal capacity in many aspects of their lives, including sexual and reproductive rights. This reality is particularly prevalent for those with intellectual or psychosocial disabilities. Pervasive and impactful violations in this sphere range from forced sterilization and denials of the right to marry, to restrictions on decision-making regarding intimate relationships and parenthood.

Around the world, many women with intellectual or psychosocial disabilities have their legal capacity denied by laws permitting substitute decision-making. In other cases, women with disabilities may technically have a right to make their own decisions but, in practice, other people are allowed to make decisions for them. This is often the case for women with intellectual disabilities and women with psychosocial disabilities, who regularly experience these informal denials of their right to legal capacity. By focusing only on formal legal capacity violations, an important part of the problem remains unaddressed.

The Research

This research was a collaborative effort led by Women Enabled International (WEI), the Disability Rights Fund (DRF), Transforming Communities for Inclusion (TCI) Global, Inclusion International, Asociación Liber (Liber), Kenya Association of the Intellectually Handicapped (KAIH), Psychiatric Survivors Association of Fiji (PSA), Self-Advocates Becoming Empowered (SABE), and Triumph Mental Health Support and Recovery Program (TRIUMPH).

The research focuses on women with intellectual disabilities and women with psychosocial disabilities, as they are disproportionately impacted by legal capacity restrictions² and are often excluded from the mainstream sexual and reproductive health and rights (SRHR) movement. Anecdotal reports indicate that gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities similarly experience a heightened risk of legal capacity violations, but given the lack of data on gender-diverse persons, including within our field research, this report focuses specifically on cisgender women.

The research utilized an inclusive and participatory methodology, with women with intellectual disabilities and women with psychosocial disabilities meaningfully engaged as both researchers and participants. First, global desk research was conducted on these issues. Field research then took place in Fiji, Kenya, Spain, Uganda, and the United States, through which we talked with over 100 women with intellectual disabilities and women with psychosocial disabilities.

The purpose of this research was to:

- > Document the ways in which women with intellectual disabilities and women with psychosocial disabilities are denied their right to legal capacity in the context of sexual and reproductive health and rights;
- > Identify community-created and led promising practices to advance the implementation of the right to legal capacity in the sexual and reproductive health context and beyond; and
- > Provide recommendations to prevent and provide redress for legal capacity violations in the context of sexual and reproductive health and rights and encourage key actors to be part of the solution.

The findings of the field research and additional global desk research indicate global trends—the seven global findings in this report.

The Global Findings

Upon review of the global desk research and field research findings, seven global trends emerged. These global findings are based on the legal capacity violations women with intellectual disabilities and women with psychosocial disabilities experience in the context of sexual and reproductive health and rights. The human rights violations in these findings are analyzed in light of the rights guaranteed in the Convention on the Rights of Persons with Disabilities.



Global Findings

Finding 1: Women with intellectual disabilities and women with psychosocial disabilities are prevented from making free and informed decisions about their healthcare, particularly their sexual and reproductive healthcare.

Finding 2: Women with intellectual disabilities and women with psychosocial disabilities are denied access to essential information about their bodies, rights, and intimate relationships.

Finding 3: Women with intellectual disabilities and women with psychosocial disabilities are forced or coerced into abortion, contraception, and sterilization.

Finding 4: Women with intellectual disabilities and women with psychosocial disabilities face numerous restrictions on their right to make decisions about parenthood.

Finding 5: Women with intellectual disabilities and women with psychosocial disabilities are deprived of the right to make their own decisions about marriage.

Finding 6: Institutionalization fuels legal capacity violations in the sexual and reproductive health and rights context.

Finding 7: Gender-based violence can be both a cause and a consequence of legal capacity violations.

The Way Forward



Promising Practices

Organizations and governments in different regions around the world are utilizing promising practices to advance the right to legal capacity—especially in the SRHR context—that could be replicated worldwide. For example:

- > An organization from the Pacific region provides healthcare providers with the training and tools they need to support persons with intellectual disabilities in making their own decisions about their sexual and reproductive health.
- > An organization from the African region runs a 24/7 toll-free helpline that provides psychosocial support and mental health first response, as well as information to inform decision-making and informed consent in healthcare and various social settings.



Recommendations

Many actors can contribute to solving these human rights violations.

Key recommendations include:

> **Law and policymakers**

To abolish substitute decision-making regimes and discriminatory legal frameworks that take away legal capacity, repeal all forms of forced reproductive practices, and redirect funds from institutions to supported decision-making and community-based mechanisms to support inclusive and rights-based access to SRHR.

> **Families and others providing support to women and gender-diverse persons with disabilitiesⁱ**

To respect the autonomy of women and gender-diverse persons with disabilities and to facilitate access to information and tools for women to make sexual and reproductive decisions.

> **Sexual and reproductive healthcare providers**

To always seek free and informed consent from women and gender-diverse persons with disabilities and to respect their will and preferences, even when they choose not to receive support from their families.

> **Organizations of persons with disabilities**

To strengthen cross-movement collaboration with sexual and reproductive health and rights organizations and feminist organizations in order to define a common advocacy strategy toward guaranteeing the effective implementation of the right to legal capacity in sexual and reproductive decision-making.

> **Sexual and reproductive rights organizations**

To center legal capacity as a crucial issue in the SRHR agenda, recognizing that without the effective implementation of the right to legal capacity, SRHR and bodily autonomy will not be guaranteed to all.

ⁱ Gender-diverse persons with disabilities are included in the recommendations because, while there is insufficient data on gender-diverse persons with disabilities in this report and beyond, we recognize that there will be no effective implementation of the right to legal capacity without considering the experiences of gender-diverse persons.

Introduction

The right to legal capacity is guaranteed to all adults and is a prerequisite to enjoying many other rights.³ Yet, for many persons with disabilities, particularly women with intellectual disabilities and women with psychosocial disabilities, the freedom to make decisions independently—or with self-chosen support—and without coercion is rare.

One of the contexts in which these violations routinely occur is within the arena of sexual and reproductive health and rights. These rights violations may involve formal substitute decision-making regimes, but often, informal mechanisms deny women their right to legal capacity. They are rights violations in themselves, and they also lead to or stem from other human rights violations, such as institutionalization, gender-based violence (GBV), poor access to information, and the denial of the broader right to health.

Many lawmakers, policymakers, service providers (healthcare, residential, education, day program, and related professionals), and family members do not realize the scope and harm of the legal capacity violations faced by women with intellectual disabilities and women with psychosocial disabilities. Many also lack information about potential solutions to these violations.

This report aims to address these gaps by:

Illuminating the ways in which women with intellectual disabilities and women with psychosocial disabilities across the world are denied their right to legal capacity in sexual and reproductive health and rights decisions.

Offering recommendations and promising practices to ensure that all women with disabilities are supported to make free and informed decisions about their lives and their bodies, particularly in the context of sexual and reproductive health and rights.

This report is based on global research on the right to legal capacity in the context of sexual and reproductive health and rights. This includes global desk research and field research conducted in five countries—Fiji, Kenya, Spain, Uganda, and the United States. Over 100 women with intellectual or psychosocial disabilities participated in the focus groups and interviews conducted during the field research.

Understanding the Right to Legal Capacity and its Violations in the Context of Sexual and Reproductive Health and Rights

What is the right to legal capacity?

The right to legal capacity consists of two inseparable elements:

- > The right to hold rights and duties (legal standing); and
- > The right to exercise those rights and duties by yourself (legal agency).⁴

This means everyone has a right to make decisions and have those decisions recognized by law and respected by others. These decisions can relate to many aspects of someone's life, such as undergoing a healthcare procedure, opening a bank account, or buying a house.⁵ Indeed, people's freedom to make any decision is an important part of this right.⁶ All decisions people make, even small ones, contribute to the full exercise of the right to legal capacity.

The right to legal capacity requires that support in decision-making be made available to all persons with disabilities. Among other things, this support:

- > Must be based on the person's will and preference rather than their perceived **best interests**;⁷
- > Must be free or affordable to the person receiving support;⁸
- > Cannot be contingent on a person's level of support needs;⁹
- > Cannot be mandatory;¹⁰ and
- > Cannot be limited because of the person's level of support needs.¹¹

Click on each term to see its definition

Understanding the Right to Legal Capacity and its Violations

Legal capacity must not be conflated with mental capacity, a controversial concept often used to deny a person's legal capacity.¹² The conflation of these two distinct concepts—and the laws based upon it—do not abide by international human rights standards, as:

- > Legal capacity is inherent in all persons;¹³
- > Mental capacity varies from one person to another;¹⁴
- > Mental capacity can vary for a given person from time to time;¹⁵ and
- > Mental capacity is not an objective and scientific criterion.¹⁶

Under international human rights law, every adult has the right to fully exercise their legal capacity, but too often, persons with disabilities are denied this right. This happens because most countries have laws that allow for **substitute decision-making**. Substitute decision-making laws allow a person to be legally appointed to make decisions on behalf of someone else. Guardianship is the most common example of a law that allows for substitute decision-making. However, any statutory regime that permits substitute decision-making is a legal capacity violation.¹⁷

Persons with intellectual disabilities and **persons with psychosocial disabilities** are disproportionately impacted by substitute decision-making regimes.¹⁸ However, because disability is often used as a reason to justify substitute decision-making, all persons with disabilities can be affected by the denial of legal capacity. The Convention on the Rights of Persons with Disabilities (CRPD) pays special attention to legal capacity and guarantees the right to it under Article 12, *Equal recognition before the law*. The Committee on the Rights of Persons with Disabilities (CRPD Committee) makes clear that states must end substitute decision-making in all its forms to guarantee the right to legal capacity.¹⁹ The right to legal capacity can also be called “the right to have rights.”²⁰ In plain language, it is usually explained as the right to make decisions, which captures the essence of this right.

The right to legal capacity does not only concern persons with disabilities, and the protections for this right extend beyond the CRPD. It is guaranteed in several international treaties and declarations,²¹ as anyone—particularly those with intersecting identities—can experience legal capacity violations. For example, women in many countries face widespread legal capacity violations, with male figures such as fathers or husbands making decisions for them. To respond to this, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) guarantees the right to equality of women before the law in Article 15.

How can the right to legal capacity be violated?

There are many ways in which the right to legal capacity can be violated. These violations can be formal or informal.

A **formal denial of legal capacity** occurs when others, such as a guardian, have the legal power to make decisions for someone or when the law forces a person to make a decision against their will. Formal denials of legal capacity can also be called *de jure* denials of legal capacity and are based on laws that substitute a person's decision-making for someone else's. Guardianship and conservatorship are the most well-known examples of this kind of law.²²

A formal denial of legal capacity means a person has no power to make certain important decisions. For example, the famous singer Britney Spears was under conservatorship for many years, during which she was unable to decide for herself when to remove her intrauterine device (IUD), a contraceptive method. Her conservator had been given the power to make that decision for her. He would not allow its removal,²³ thereby controlling her decision about if and when to have children.

Many persons with disabilities face no formal legal restrictions on their legal capacity. However, this does not mean all of them are allowed to make their own decisions, as many persons with disabilities commonly face informal denials of their right to legal capacity. By focusing only on formal legal capacity violations, an important part of the problem remains unaddressed.

An **informal denial of legal capacity** occurs when there is no law (like a guardianship law) that says others have the legal power to make decisions for someone, but they are still denied the right to make their own decisions. This occurs when service providers, family members, or others make decisions for a person even though they have no legal authority to do so. One example of an informal denial is when a person with a disability has no guardian, but a healthcare provider accepts a family member's consent for a medical procedure without seeking free and informed consent from the person with a disability. Informal denials of legal capacity can also be called *de facto* denials of legal capacity or *de facto* guardianship.

Informal denials of legal capacity can be just as harmful as formal denials, and they have been well documented by the disability movement.²⁴ Despite this, these violations usually receive less attention in formal literature.

Thankfully, this has been improving. In its Concluding Observations, the CRPD Committee has increasingly referred to *de facto* guardianship and expressed its concern about these practices.²⁵ The Committee has also made clear that *de facto* deprivations of the right to legal capacity violate Article 12 of the CRPD.²⁶ Therefore, to guarantee the right to equal recognition before the law, it is crucial to understand and prevent both formal and informal denials of legal capacity.

What are some examples of legal capacity violations?

There are many examples of legal capacity violations. Common violations include denying a person the right to:

- > Control their own money
- > Get married
- > Seek and refuse medical treatment
- > Choose where or with whom they live

Too often, others—such as guardians, service providers, and family members—make decisions about the lives of persons with disabilities without their knowledge or consent.

Persons with disabilities may also be denied the chance to make smaller, day-to-day choices about their own lives. Being prevented from making decisions such as what and when to eat, what to wear, or how and with whom to spend free time negatively impacts one's ability to make the large, impactful decisions discussed above, and it can lead to other legal capacity violations. This is because being prevented from making small choices makes it very difficult for individuals to learn how to make larger decisions for themselves.

Why is it important to focus on the right to legal capacity of women with intellectual disabilities and women with psychosocial disabilities?

Frequently, persons with disabilities experience harmful stereotypes that they are incapable of making important life decisions. Women similarly encounter discriminatory stereotypes about their decision-making capacity due to their gender. As a result, women are denied their legal capacity more often than men, and persons with disabilities are denied their legal capacity more often than persons without disabilities.

For women with intellectual disabilities and women with psychosocial disabilities, these harmful stereotypes compound, exacerbating the discriminatory perception that they are unable to make decisions for themselves.²⁷ Even in countries where legislation does not authorize substitute decision-making, it is common practice for service providers or family members to make decisions on behalf of women with intellectual disabilities and women with psychosocial disabilities. As a result, women with intellectual disabilities and women with psychosocial disabilities are disproportionately impacted by both formal and informal legal capacity restrictions. Accordingly, there must be specific efforts to ensure the right to legal capacity is guaranteed to women with intellectual disabilities and women with psychosocial disabilities.

It is important to note that while there can be overlap between the intellectual and psychosocial disability communities—as there are many persons who identify as a person with both an intellectual and a psychosocial disability—they are two different groups in the disability community. As such, the barriers these distinct communities face to exercising their right to legal capacity should not be considered the same in all circumstances. Many of the differences and nuances in how legal capacity violations impact the exercise of sexual and reproductive health and rights (SRHR) of women with intellectual disabilities and women with psychosocial disabilities are highlighted in this report. Still, most of the time, the findings from both communities are presented together to allow the report to highlight connections and common patterns.

Gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities

Gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities experience intersectional discrimination based on both disability and gender.²⁸ However, there is little disaggregated research on these populations, and our field research did not sufficiently capture the lived experiences of gender-diverse persons. It is necessary to dedicate future research to understanding how legal capacity restrictions in the context of sexual and reproductive health and rights impact the lives of gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities, particularly given the serious human rights threats that the broader gender-diverse community is facing globally. It is also crucial to recognize that 1) gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities are often subject to erasure in laws, policies, and research, and 2) there will be no effective implementation of the right to legal capacity without taking into account the experiences of gender-diverse persons. Therefore, this report recognizes this gap and refers to gender-diverse persons with disabilities where it can, including in the Recommendations and Promising Practices sections, as they are key to identifying and implementing solutions to this issue.

What are sexual and reproductive health and rights and why are they the focus of this research?

Sexual and reproductive health and rights are rights related to our bodies, relationships, sex, pregnancy, and having children. They include access to a full range of sexual and reproductive health information, goods, and services, including contraception, comprehensive sexuality education, prenatal care, safe delivery and postnatal care, parental leave, access to abortion services, preventive care, and testing and treatment of sexually transmitted infections and infertility.²⁹

These rights are guaranteed by many treaties, including the CRPD, in which they connect to the rights to:

- > Equality and non-discrimination (Article 5)
- > Accessibility (Article 9)
- > Life (Article 10)
- > Equal recognition before the law (legal capacity) (Article 12)
- > Liberty and security of the person (Article 14)
- > To be free from torture or cruel, inhuman or degrading treatment or punishment (Article 15)
- > Protecting the integrity of the person (Article 17)
- > Access to information (Article 21)
- > Respect for privacy (Article 22)
- > Respect for home and the family (Article 23)
- > Education (Article 24)
- > Health (Article 25)
- > Work and employment (Article 27)³⁰

Sexual and reproductive health and rights are particularly connected to the right to legal capacity, as they encompass:

- > The freedom to make decisions about sexual and reproductive health;
- > The freedom to decide if, when, and how often to have children;
- > The right to give informed consent to sexual and reproductive health procedures;
- > The right to decide if, when, and which support to receive to exercise sexual and reproductive rights;³¹ and
- > The right to have control over these decisions without discrimination, coercion, or violence.³²

Sexual and reproductive health and rights are a crucial issue for all women, including those with disabilities. Many times, however, issues at the intersection of disability and gender have not been sufficiently prioritized within either the disability or women's rights movements. Consequently, many of the common legal capacity issues that primarily affect women with disabilities are overlooked and under-researched. Therefore, this report seeks to fill a gap in the research on legal capacity and to bring a gender lens to the advocacy and policy work being done to protect and guarantee the right to legal capacity for women with disabilities.

What is bodily autonomy and how does it relate to legal capacity?

The right to legal capacity is a prerequisite to ensuring bodily autonomy.³³

Bodily autonomy means being able to make decisions about your body and personal life without discrimination, violence, or coercion.³⁴ This includes deciding when, if, or with whom to have sex. It also includes deciding when, if, or with whom you want to become pregnant, when and if you want to have children, and how many children to have. While bodily autonomy is not explicitly stated as a standalone right in human rights treaties, it gathers the elements of two key fundamental rights: legal capacity and sexual and reproductive health. This report aims to ensure that the experiences of women with disabilities exercising their legal capacity in the context of sexual and reproductive health and rights are included in efforts to advance the right to bodily autonomy.

What is informed consent and how does it relate to legal capacity?

Informed consent is more than asking a person with a disability—or anyone—for a signature before a medical procedure. It is a process of communication between a healthcare service provider and a person with a disability that results in the person with a disability giving, withdrawing, or refusing to give permission for a procedure based on full knowledge of a procedure.³⁵ It requires clearly explaining the purpose, nature, consequences, and risks of the procedure, including in plain language and other accessible formats.³⁶

Understanding the Right to Legal Capacity and its Violations

According to the International Federation of Gynecology and Obstetrics (FIGO), informed consent is “a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- > (a) the diagnostic assessment;
- > (b) the purpose, method, likely duration, and expected benefit of the proposed treatment;
- > (c) alternative modes of treatment, including those less intrusive; and
- > (d) possible pain or discomfort, risks, and side effects of the proposed treatment.”³⁷

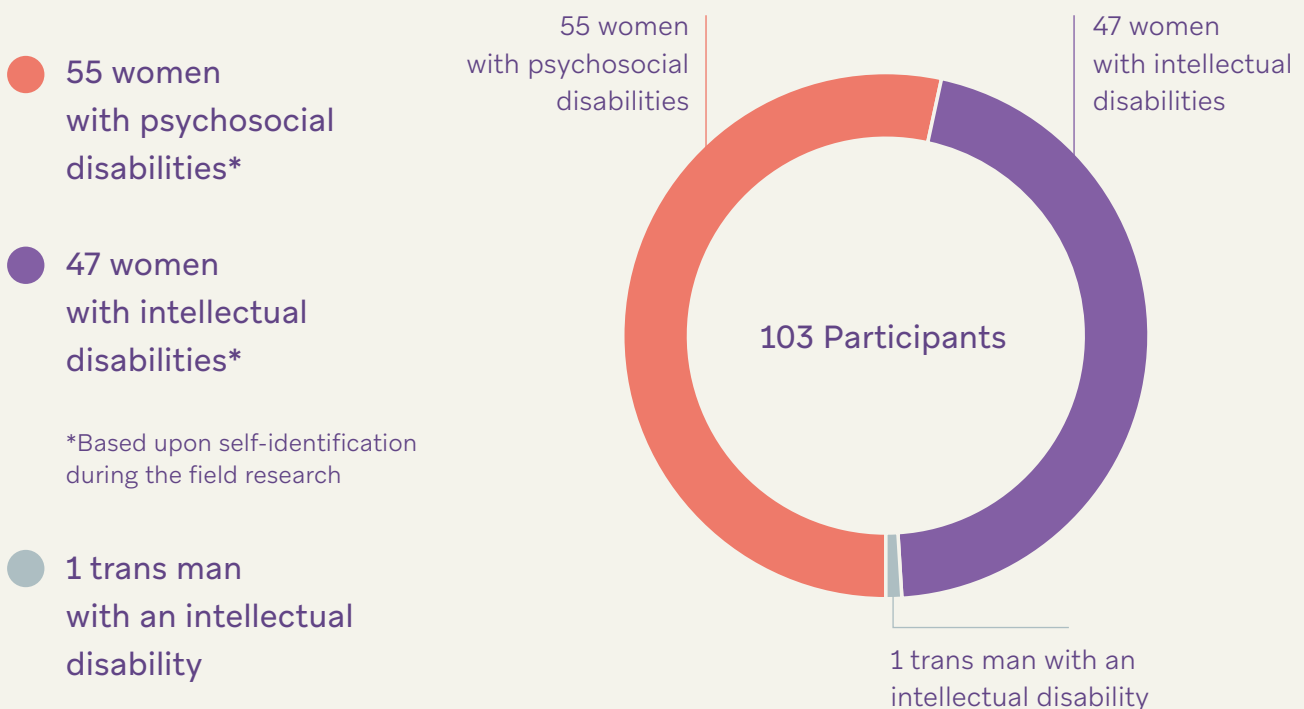
When seeking informed consent, service providers should never assume a person lacks the capacity to provide it.³⁸ Indeed, and as clearly stated by FIGO, challenges in obtaining informed consent (for example, due to communication or other access needs) do not relieve professionals from their duty to pursue fulfillment of this requirement.^{ii 39} The right to legal capacity, when exercised in the context of sexual and reproductive health, entails the right to healthcare based on free and informed consent.⁴⁰ It is the service provider’s obligation to ensure that this and other rights of the person with a disability are respected throughout the informed consent process.⁴¹

ⁱⁱ Although FIGO refers to the obligation to involve persons with intellectual disabilities in the decision-making process of a procedure, FIGO’s guidelines regarding intellectual disability are incompatible with the requirements of the CRPD, as these guidelines refer to a “joint decision maker” and to the person’s best interests.

Methodology

Research on legal capacity—and, more broadly, on issues that disproportionately impact women with disabilities—often overlooks the lived experiences and expertise of women with intellectual disabilities and women with psychosocial disabilities themselves. From start to finish, this project aimed to do things differently.

To inform this report, Women Enabled Internationalⁱⁱⁱ partnered with eight organizations of persons with disabilities to conduct inclusive research, composed of global desk research and field research (focus groups and/or interviews) in five countries. The focal countries were selected to understand how issues related to legal capacity play out within distinct legal and policy frameworks, particularly across a range of regions, cultures, and income levels. One hundred and three (103) persons with disabilities participated in the focus groups or interviews conducted during the field research, namely:



All the quotes and lived experiences included in this research come from the women with disabilities who participated in the focus groups or interviews. To protect their privacy, the names associated with their lived experiences are all pseudonyms.

ⁱⁱⁱ Women Enabled International (WEI) is an international non-governmental organization of feminists with disabilities and allies that works to advance human rights and justice at the intersection of gender and disability to challenge exclusionary, unjust systems and support the leadership and center the voices of women, girls, and gender-diverse people with disabilities globally.

International partners:

- > Disability Rights Fund (DRF)^{iv}
- > Inclusion International^v
- > Transforming Communities for Inclusion (TCI) Global^{vi}

National-level partners:

Organizations of persons with intellectual disabilities (Inclusion International Members):

- > Asociación Liber (Liber), Spain^{vii}
- > Kenya Association of the Intellectually Handicapped (KAIH), Kenya^{viii}
- > Self-Advocates Becoming Empowered (SABE), the United States^{ix}

^{iv} Disability Rights Fund (DRF) supports disability rights movements to unleash their power and celebrate diversity, valuing the participation, access, and inclusion of all people with disabilities, in the promotion of human rights.

^v Inclusion International is the global network of people with intellectual disabilities and their families. The network is made up of organizations of persons with disabilities that represent people with intellectual disabilities and their families around the world.

^{vi} Transforming Communities for Inclusion (TCI) Global is a membership-based global organization of persons with psychosocial disabilities. Empowered by the extraordinary vision and guidance of the Convention on the Rights of Persons with Disabilities, TCI's purpose is to situate persons with psychosocial disabilities at the center of the cross-disability movements at the national, regional, and global levels, to reclaim their dignity and autonomy and experience independence to realize their right to live in the community.

^{vii} Asociación Liber de Entidades de Apoyo is a nationwide network that brings together 37 non-profit organizations across Spain, all dedicated to supporting adults with intellectual, developmental, or psychosocial disabilities in exercising their legal capacity. Liber focuses on strengthening the disability movement, and promoting a model of support that upholds individuals' will and preferences in decision-making. With an inclusive approach, Liber actively encourages participation and self-determination, working to advance the leadership of people with disabilities.

^{viii} The Kenya Association of the Intellectually Handicapped (KAIH) is a pioneering organization dedicated to advocating for the rights and inclusion of persons with intellectual disabilities and their families. With over two decades of experience, KAIH empowers thousands through education, advocacy, and community engagement. Representing over 3,000 members across 10 counties, the organization is committed to creating a society where the human rights of people with intellectual disabilities are fully recognized and respected.

^{ix} SABE is a national self-advocacy organization in the United States. Each state is part of a region, and each SABE board member is a person with a disability. SABE works on many different issues—for example, making our own decisions, healthcare, voting, and deinstitutionalization. SABE believes that people with disabilities should be given the same decisions, choices, rights, responsibilities, and chances to speak up and empower themselves as non-disabled people.

Methodology

Organizations of persons with psychosocial disabilities (TCI Global Members):

- > Psychiatric Survivors Association (PSA), Fiji^x
- > Triumph Mental Health Support and Recovery Program (TRIUMPH), Uganda^{xi}

Commitment to an inclusive project

Centering the leadership of women with intellectual disabilities and women with psychosocial disabilities—both as researchers and participants—was a crucial pillar of the project. To achieve this goal, WEI and partners developed an inclusive methodology for the research using two guidelines as a foundation:

- > The “[Listen Include Respect Guidelines](#),” a set of guidelines to help organizations fully include persons with intellectual disabilities in their work, such as in meetings, project management, and research. It was developed by Inclusion International and Down Syndrome International.
- > The document, “[Guidelines for making events and activities \(in person and online\) inclusive and accessible for persons with psychosocial disabilities](#),” developed by TCI Global.

In line with these guidelines and the spirit of the project, women with intellectual disabilities and women with psychosocial disabilities led the field research, providing input into the methodology and research materials and moderating the focus groups and interviews. All project materials were written directly in plain language or had a version that was easy to understand.

^xPSA is a non-governmental organization and one of the five organizations of and for persons with disabilities in Fiji. It champions the voices and rights of those with psychosocial disabilities through peer support, advocacy, awareness, and community-building. PSA is dedicated to creating a more inclusive, rights-respecting society for individuals with psychosocial disabilities in Fiji.

^{xi}Triumph Uganda Mental Health Support and Recovery program (TRIUMPH) is an indigenous organization founded by persons with psychosocial disabilities who have walked the mental health recovery journey in Uganda. TRIUMPH contributes to the process of enhancing recovery, building resilience, and investing in social networks for the inclusion of persons with psychosocial disabilities.

Methodology

The methodology also included partner-to-partner collaboration and learning. The partners at the national level were trained to conduct the research in their countries. For the organizations of persons with intellectual disabilities, a [self-advocate](#) staff member of Inclusion International led the training. For the organizations of persons with psychosocial disabilities, the Secretariat team of TCI Global provided the training.

Ownership of the project

Another crucial pillar of the methodology was ensuring all partners felt the project was their own and felt empowered to make decisions. While recognizing the power dynamics in the project, we designed the methodology to be as horizontal as possible, with partners leading the decisions related to how to conduct the field research and what topics to prioritize in the questions. This enabled partners to share their invaluable expertise about each local context.^{xii}

To ensure self-advocates were meaningfully included in the report development and review process, we created a reference group of the self-advocates staffed on the project, led by an experienced self-advocate. In periodic meetings, the self-advocates provided input into the report's findings, conclusions, recommendations, and format. The reference group also developed a more accessible, easy-to-understand version of the report.

^{xii} For example, when planning the United States focus groups, the research team realized that one of the partners qualified as a mandated reporter. Though the exact definition of a mandated reporter varies by U.S. state, mandated reporters are generally persons who are required by law to report abuse or suspected abuse of children, persons with disabilities, or older persons. Typically, a person is designated as a mandatory reporter because of their profession. *What is a Mandated Reporter?*, NAT'L ASS'N OF MANDATED REPS., (2021), <https://namr.org/news/what-is-a-mandated-reporter>. Understanding that having a mandated reporter in the room could impact participants' willingness to share—and recognizing the significant harm that mandated reporting has caused in some communities in the United States, particularly in communities of color—the research team had many discussions about how to move forward. See, e.g., *Racial (In)Justice in the U.S. Child Welfare System: Response to the Combined Tenth to Twelfth Periodic Reports of the United States to the Committee on the Elimination of All Forms of Racial Discrimination*, CHILD'S RTS. & COLUMBIA L. SCH. HUM. RTS. INST., (July 2022), <https://www.childrensrights.org/wp-content/uploads/imported-files/Childrens-Rights-2022-UN-CERD-Report-FINAL.pdf>; and Shereen White & Stephanie Marie Persson, *Racial Discrimination in Child Welfare is a Human Rights Violation—Let's Talk About It That Way*, AM. BAR ASS'N, (Oct. 13, 2022), <https://www.americanbar.org/groups/litigation/resources/newsletters/childrens-rights/racial-discrimination-child-welfare-human-rights-violation-lets-talk-about-it-way/>.

Ultimately, partners decided to: 1) allow that partner to be in room for the focus groups; 2) provide a plain language explanation of what a mandated reporter is (and the possible consequences of mandated reporting) to all participants prior to beginning the focus groups; and 3) offer a separate space in which participants could share responses with someone who was not a mandated reporter.

Inclusive hiring process

Each research partner conducting field research with persons with intellectual disabilities staffed or hired a self-advocate to lead the focus groups and interviews. Those partners received guidance on an inclusive hiring process to select the candidates. Self-advocate leadership was essential to guaranteeing inclusive and successful field research, as it recognized women with intellectual disabilities' expertise about their own lived experience and their community.

The research participants

The national-level partners recruited the research participants to be part of the focus groups or interviews from their networks, choosing persons who reflected a variety of ages, races and ethnicities, living arrangements, and guardianship statuses. All participants were above 18 years old at the time of the field research.

The partners made an effort to include gender-diverse persons with intellectual disabilities and gender-diverse persons with psychosocial disabilities in the research. However, only one gender-diverse individual participated in the field research. Given that, we were unable to draw conclusions that could be considered representative of this diverse community.

The research aimed to be inclusive of and meaningful to the participants, ensuring they would benefit directly from participating, rather than only contributing to the research process. In each country, the participants received resources about local healthcare and NGO services working on increasing access to quality sexual and reproductive healthcare, GBV prevention and response, and accessible SRHR information. The participants also received information on how to access counseling and services to address any trauma triggered by the research process. In Uganda, the participants also joined a counseling session that addressed trauma, healing, and collective care. The sessions were organized to respond to the many traumatic experiences shared by women about GBV and institutionalization.

Honorarium

Participants received an honorarium for their participation in the focus groups or interviews, in recognition of their time. The research team explained the purpose of the payment to the participants and took ethical matters into account, making clear that the honorarium should not influence their opinions or participation in the research. The honorarium responds to the demand from women and gender-diverse persons with disabilities to receive compensation for their time and expertise when invited to take part in projects, focus groups, or events. Accessibility-related stipends were also offered to remove barriers to participation.

Global Findings

This section analyzes seven widespread ways that women with intellectual disabilities and women with psychosocial disabilities experience legal capacity violations in the context of sexual and reproductive health and rights. These violations were reported by women across multiple countries where the field research was conducted. The striking consistency of these violations across distinct contexts, along with additional global desk research, indicates that these violations are global trends.

These global findings intentionally focus on legal capacity violations in the SRHR context experienced by women with intellectual disabilities and women with psychosocial disabilities, based on what the women who took part in the field research described. The human rights violations in these findings are analyzed using the rights guaranteed in the CRPD as a framework.

The concept of ableism is key to understanding why these legal capacity violations happen. Ableism is a belief system rooted in the negative perceptions of the value of persons with disabilities.⁴² As a result, ableism implies that “the disability experience [is] a misfortune that leads to suffering and disadvantage and invariably devalues human life.”⁴³ Ableist thinking leads to discrimination against and oppression of persons with disabilities in many contexts, as it may inform legislation, policies, and practices.⁴⁴ Beyond ableism, the causes of legal capacity violations are numerous, intersecting, and often complex. They include, but are not limited to:

- > Additional structural barriers, such as patriarchy, colonialism, racism and white supremacy, ageism, and poverty;⁴⁵
- > A continuation of legal guardianship and other laws that permit substitute decision-making;
- > Harmful stereotypes about disability and gender;⁴⁶
- > Power dynamics and hierarchies within families and communities that disadvantage women with disabilities;⁴⁷
- > The pressure families can experience to (over)protect their family members with disabilities;⁴⁸ and
- > A lack of **supported decision-making** systems.

Exploring these causes in depth falls outside the scope of this report. Nevertheless, it is important to bear in mind that the legal capacity violations described in the findings in this report are connected to these complex causes and should be read from this intersectional perspective.

Finding 1: Women with intellectual disabilities and women with psychosocial disabilities are prevented from making free and informed decisions about their healthcare, particularly their sexual and reproductive healthcare.

Sexual and reproductive health and rights and bodily autonomy are inextricably linked to the right to legal capacity, as they encompass the right to have control over decisions concerning sexuality and reproduction without discrimination. A human rights-based approach to sexual and reproductive health places autonomy and decision-making at the center of law and policymaking related to sexual and reproductive health services.⁴⁹

The right to legal capacity in the sexual and reproductive health and rights context requires that everyone, including women with intellectual disabilities and women with psychosocial disabilities, has the right to:

- > Choose or refuse treatment;⁵⁰
- > Give free and informed consent to medical procedures;⁵¹ and
- > Have safeguards against forced treatment and/or procedures in place.⁵²

Healthcare decision-making and legal capacity violations

Too often, women with intellectual disabilities and women with psychosocial disabilities are denied the opportunity to exercise their legal capacity in relation to their own bodies, including regarding their sexual and reproductive health.

This can be true even when there is no legally appointed guardian in place. Several women with disabilities we spoke with reported that they had been treated by healthcare providers as if they were under guardianship, regardless of whether they were or not. When this happens, healthcare providers may themselves make decisions for women, or they may seek approval from a parent or other professional without regard for that woman's legal status to make her own medical decisions.

“ When I went to see a gynecologist about my abnormal menstrual cycle, I first met the nurse, opened up about my history of depression, and the nurse’s attitude changed. When the doctor received my form and saw the history of depression, I was told to undress and lay on the bed. I was left unattended while I lay naked on the bed. The doctor made choices for me. I felt I had lost my dignity. That day, I left traumatized and never wanted to see another doctor. He didn’t respond to the questions I asked him but told me to follow his directions.”

– A woman with a psychosocial disability in Uganda

“ I am my own guardian; I have always been my own guardian...And [the hospital] treated me terribly in this department, and they wouldn’t let me sign my own discharge papers. They kept treating me like I wasn’t my own guardian, kept asking my staff stuff. They called my mom of all people [and] I’ve not seen my mom in months...And they just kept treating me terribly and not acting like I was my own individual...”

– A woman with an intellectual disability in the United States

Some women also talked about how their families denied their legal capacity by controlling their healthcare decision-making—often explicitly using disability as their justification for doing so.

“ If I’m feeling a bit under the weather, I tell my mom, and we plan a checkup together. But mostly, she makes the decision because of my disability.”

– A woman with a psychosocial disability in Fiji

The consequences of these violations

The consequences of this kind of control over decision-making on the well-being of women with disabilities can be significant.

“ My parents decide for me [about my sexual and reproductive health] so many times. I have learned to adjust as I grow. Initially, I would suffer and experience anxiety, anger, and depression, but now I just let it go. Life cannot give you what you want most times.”

- A woman with a psychosocial disability in Uganda

Global Findings | Finding 1

Despite what many may think, when others overprotect women with intellectual disabilities and women with psychosocial disabilities by making healthcare decisions for them, it does not keep women healthier. Rather, in addition to being a legal capacity violation, it regularly corresponds to women with disabilities not accessing healthcare at all—a form of violence recognized by the United Nations.⁵³

For example,



Dembe is a 20-year-old woman^{xiii} with a psychosocial disability who lives in Uganda. She is consistently denied the right to make healthcare decisions by her parents. Dembe explained, “My parents decide for me almost everything. Sometimes, there are things that are important to me, but they don’t find important. For example, I normally want to go for a health checkup when I feel I have an infection, but my mother doesn’t see the need [for me] to go for it. I don’t make any decisions because I already know the feedback I will get from my family. They won’t approve of my decisions unless it is an emergency or crisis case.”

^{xiii} Throughout this report, vignettes (like Dembe’s) include the participants’ ages when they gave consent for this information to be included in the report.

Healthcare decision-making and the medical model of disability

Unfortunately, Dembe’s experience is not unique. Many women with psychosocial disabilities we talked to shared that they had been deprived of sexual and reproductive healthcare when families or healthcare providers made decisions for them, because psychiatric services are prioritized above all other healthcare. When psychiatric diagnosis becomes the default lens through which all health needs are interpreted, health concerns—even when unrelated to mental health, like gynecological exams or contraception consultations—are routinely redirected back to psychiatric settings. This common practice results in women with psychosocial disabilities being denied the opportunity to access comprehensive healthcare, violating their right to health and reproductive autonomy as guaranteed under Article 25 of the CRPD.

This focus on psychiatric care only, to the detriment of sexual and reproductive healthcare, also undermines women with disabilities’ identity as women and is grounded in the medical model of disability.

According to the medical model of disability, disability is a synonym for impairment and is something to be treated, fixed, or cured. The medical model of disability considers there to be a normal health status, and any form of disability is seen as a deviation from that status to be fixed if possible.⁵⁴ In particular, persons with psychosocial disabilities are treated solely as patients within this model. This status entails that they should only interact with mental healthcare or psychiatric systems.

Increasingly—and in particular, since the adoption of the CRPD—society is evolving towards social and human rights models of disability, which see inaccessible environments as what needs fixing, not individuals.⁵⁵ Nevertheless, the medical model is still ingrained in many systems and behaviors, including healthcare practice. Consequently, when women with disabilities have their healthcare decisions made by others, they face deeply entrenched attitudinal barriers to receiving any healthcare attention that is not disability related.

“ I know and see the need to go for checkups, but it is not taken as important to my family to access the health services related to my health as a woman.”
– A woman with a psychosocial disability in Uganda



Key takeaways

- > Formal and informal denials of legal capacity prevent women with disabilities from making their own decisions about their sexual and reproductive health, including the decision to access sexual and reproductive healthcare in the first place.
- > The healthcare needs of women with intellectual disabilities and women with psychosocial disabilities are often reduced to their disability. This can lead the people making decisions on their behalf to deny them access to other types of healthcare that they would otherwise seek out, including sexual and reproductive healthcare.

Finding 2: Women with intellectual disabilities and women with psychosocial disabilities are denied access to essential information about their bodies, rights, and intimate relationships.

Robust, balanced, and accessible information on SRHR is a foundational support needed for SRHR decision-making. It is essential for women to meaningfully exercise their right to legal capacity in the context of SRHR,⁵⁶ as it helps women understand their options and make informed decisions about their own lives.

Due to the widespread exclusion of women with intellectual disabilities and women with psychosocial disabilities from strong community or peer networks, family members and service providers often become their main sources of SRHR information. As a result, women with disabilities often lack access to comprehensive sexuality education, and if they do have access to it, it is unlikely to be inclusive and adapted for persons with intellectual disabilities and persons with psychosocial disabilities.

Access to biased SRHR information

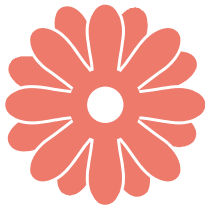
Many of the women we talked with shared that their family members had denied them access to balanced sexual and reproductive health information, effectively restricting or controlling women's SRHR decision-making by limiting the information they provide about sex and intimate relationships to information about abuse.

“ **In high school, my older sisters told me to be careful because boys would take advantage of me and get me pregnant.**”

– A woman with an intellectual disability in Spain

Even when the information provided extended beyond abuse, some women we talked with shared that their family members only provided them with certain SRHR information—such as the negative effects of intimate relationships—leading them to make the decisions family members thought were in their best interests.⁵⁷

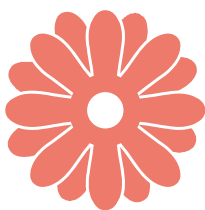
For example,



Naomi is a 27-year-old woman with a psychosocial disability who lives in Uganda. When asked whether anyone had shared SRHR information with her, she discussed her negative experience in this regard: "Yes, my auntie, though unkindly. My auntie would tell me harshly that if I slept with men, I would end up getting pregnant or getting sexually transmitted diseases."

Access to SRHR information framed by religion

Some of the women who took part in the research shared that their families limited the SRHR information they gave to women to that which was based on the family member's belief system, pushing women with intellectual disabilities and women with psychosocial disabilities into making SRHR decisions that are in alignment with those beliefs. For example,



Florence is a 28-year-old woman with a psychosocial disability who lives in Uganda. She was raised in a religious family and learned about SRHR from that perspective: "I learned [about SRHR] from conferences and church, where we were talked to about sex before marriage. My mother would emphasize that having sex before marriage would mess up my life and that I should be careful in the way I handle my body. [She would say] 'Don't mess up with men and, at the right time, you will get married. Abstain and take care of yourself. Your body is the temple of God.'"

Florence later explained how receiving this kind of information has impacted her decision-making about intimacy: "I abstain from sex till marriage. I avoid relationships and create boundaries because some people don't want to marry you...I avoid [anything that can] get [me] pregnant. My mother used to tell me when I am in a relationship to avoid being with a man [alone] in a room because it leaves room for the enemy, [if] he gets attracted to me."

Although many women raised in religious contexts receive the same type of information described above, they often have the opportunity to access information from multiple sources—such as school, friends, television, or the internet—and gather diverse perspectives from which to forge their own beliefs around SRHR. Due to widespread isolation and a lack of accessible information, many women with intellectual disabilities and women with psychosocial disabilities do not have that same opportunity. They often face barriers to accessing alternative information that brings a different perspective on SRHR, limiting their possibilities of accessing multiple sources of information to inform their decisions.

Lack of access to nearly any SRHR information

Multiple women with intellectual disabilities and women with psychosocial disabilities we spoke with had not had access to nearly any SRHR information, depriving them of the resources needed to inform their decision-making about their own bodies and intimate relationships.

One woman with a psychosocial disability in Fiji shared that the first time she was given information about sexual intimacy and getting pregnant was in the hospital after giving birth to her first child.

Two women with intellectual disabilities in Kenya spoke explicitly to how their decision-making was limited by a lack of SRHR information. When asked what support they would need to make their own decisions, one woman said, “to be informed about birth control and protection” and another shared, “to be taught more about relationships and sex.”

The women who took part in the research who were perceived to have **high support needs** and communication access needs were particularly impacted by gatekeeping of quality sexual and reproductive health and rights information.

Two Spanish women with intellectual disabilities who use informal systems of signs to communicate had no signs for the words “sex” or “contraception”—indicating that they had never been given information about nor had they been taught ways to communicate their needs and wants regarding these topics.

The way that families frame information about sex and relationships to their family member with a disability is often influenced by a variety of factors. In particular, a combination of family members’ own fears, values, and concerns, harmful stereotypes, and biased information received from doctors and other service providers can have a negative effect on the access to and information about sex and relationships that women with disabilities receive from their family members.⁵⁸ This is demonstrated in the examples above.

Families are an essential part of the solution to this problem because they often hold significant influence over whether, how, and when SRHR information is shared. Unfortunately, many professionals still emphasize to families the importance of safeguarding against abuse or avoiding pregnancy rather than the importance of protecting rights.⁵⁹ It is essential that the focus of support shifts from protectionism to upholding rights and empowerment. It is important that families are engaged to make this change a reality. This means ensuring that women with disabilities have direct access to inclusive, accurate SRHR information and that families, too, are supported to better understand their role as enablers of choice, dignity, and autonomy for women with intellectual disabilities and women with psychosocial disabilities.



Key takeaways

- > The right to legal capacity requires that support in decision-making be made available to all persons with disabilities. Comprehensive, balanced, and accessible sexual and reproductive health information is a foundational support for free and informed SRHR decision-making.
- > However, women with intellectual disabilities and women with psychosocial disabilities are frequently denied access to this information. This is especially true for those who are perceived to have high support needs and/or communication access needs.

Finding 3: Women with intellectual disabilities and women with psychosocial disabilities are forced or coerced into abortion, contraception, and sterilization.

Forced or coerced reproductive practices are involuntary procedures that strip women of their ability to get or stay pregnant, either permanently or temporarily. These practices—which include abortion, contraception, and sterilization without informed consent—violate various human rights, including the right to legal capacity, as they deny women the right to make their own decisions about their bodies and health.⁶⁰

Historically, women with intellectual disabilities and women with psychosocial disabilities have been disproportionately subject to forced or coerced reproductive practices.⁶¹ The findings of this research show that they continue to face these practices of reproductive control today.

> Forced or coerced abortion

A Kenyan woman with an intellectual disability shared that she got pregnant and was forced to have an abortion. “My mother made me have an abortion. [...] [When] I lost my child, I was really hurt.”

> Forced or coerced contraception

A middle-aged woman with an intellectual disability in the United States shared that her guardian told her she had to take birth control for many years. She sadly explained that she is now “too old to have a baby.”

> Forced or coerced sterilization:

In Fiji, a woman with a psychosocial disability shared that her mother pressured her to consent to sterilization because of her psychosocial disability. Although the woman “didn’t want that surgery”, she felt she had no choice but to go through with it.

Although many women freely choose sterilization as a form of permanent birth control,⁶² others—particularly women with intellectual disabilities and women with psychosocial disabilities—are denied the right to make their own decisions about it. Instead, they are often forced or coerced to undergo sterilization procedures.

The gravity of this violation is reflected in its characterization under international human rights law. When forced or coerced, sterilization is a form of gender-based violence (further analyzed in Finding 7). Forced sterilization has also been recognized as a form of cruel, inhuman, or degrading treatment—and in some cases, forced sterilization causes physical and psychological harm so severe and lasting that it can amount to torture.⁶³ The consequences of forced sterilization can include lasting depression, “extreme social isolation, family discord or abandonment, fear of medical professionals, and lifelong grief.”⁶⁴

When and where these violations occur

Often, these violations occur in institutional settings. The connections between institutionalization and legal capacity violations in the context of SRHR are discussed further in Finding 6.

“ The day program [for persons with intellectual disabilities] gives you oral contraception in case someone rapes you or something so that you won't get pregnant.”

–A woman with an intellectual disability in Spain

Other times, women with intellectual disabilities and women with psychosocial disabilities are coerced into agreeing to a procedure by healthcare providers who do not seek their free and informed consent. A person does not need to explicitly refuse a reproductive procedure for a legal capacity violation to take place. It can happen in more subtle ways, such as not sharing information that would ensure fully informed decision-making or pressuring someone in a vulnerable situation to agree to it.

For example,



Ariadna is a 35-year-old woman with a psychosocial disability in Fiji who experienced coerced sterilization right after labor when doctors did not seek her free and informed consent. “The doctors said it wasn’t safe for me to have another child and I should get my tubes tied. It was the day after I gave birth to my fourth child. I was not feeling well; I was depressed. There was no one to support me. The doctors didn’t discuss any other options, like using [other] contraception. So, I just signed the form. They did the surgery. After I recovered and I felt more like myself, I realized I didn’t want that surgery.”

Common justifications for these violations

These practices of reproductive control over women with disabilities are frequently rooted in harmful stereotypes that question their ability as parents—as further discussed in Finding 4—and in eugenic thinking. Eugenics is the harmful, discredited idea that the human genome should be manipulated through reproductive control to reduce the number of individuals born with certain characteristics—such as disability or a specific race or ethnicity.⁶⁵ Under this discriminatory paradigm, many persons with disabilities were forcibly sterilized throughout the 20th century.⁶⁶

While eugenic thinking continues to underpin forced reproductive measures,⁶⁷ another justification has become increasingly common: that forced abortion, contraception, and sterilization are in the best interests of women with intellectual disabilities and women with psychosocial disabilities.⁶⁸ This reasoning is grounded in the wrongful belief that persons with intellectual disabilities and persons with psychosocial disabilities are inherently vulnerable individuals in need of protection by others—such as guardians, service providers, or families.

The CRPD Committee prohibits the use of a person's best interests as justification for laws, policies, and practices that deny them the right to make decisions,⁶⁹ including decisions about their reproductive lives. Laws, policies, and practices justified on this basis constitute denials of the right to legal capacity, because the best interests framework:

- > Allows for substitute decision-making;
- > Ignores the person's **will and preferences**;
- > Applies to adults a framework that is meant only for persons under 18 years of age;⁷⁰ and
- > Reinforces harmful stereotypes about disability.

The best interests of women with disabilities are alleged in many circumstances, but this argument is particularly present in the context of reproductive choices. For example, forced contraception and sterilization are often said to be in women's best interests because of the idea that these practices could help protect women with disabilities from sexual violence.



Daniela is a woman with an intellectual disability who lives in Spain. She was coerced into agreeing to sterilization after a rape. Despite being 37 years old, she has not received regular gynecological care. The first time she saw a gynecologist was right after the sexual violence, when she was 20 years old. "I didn't want [the sterilization], but to obey my mother, I had to do it." After the sterilization procedure, Daniela never saw a gynecologist again.

However, contrary to what many believe and what concerned families are often told, forced sterilization and contraception do not protect women with disabilities against sexual violence. Instead, these practices:

- > Increase their vulnerability to sexual abuse, as the person who commits the violence is certain that pregnancy will not be a consequence of the assault;⁷¹
- > Deny the integrity of the (potential) survivor, in violation of Article 17 of the CRPD;
- > Violate the right of the (potential) survivors to be free from torture and other cruel, inhuman, or degrading treatment or punishment, in violation of Article 15 of the CRPD;⁷²
- > Expose survivors to violence and trauma, in addition to the violence and trauma experienced because of the sexual violence, in violation of Article 16 of the CRPD; and
- > Perpetuate the vicious cycle between gender-based violence and legal capacity violations, as explained in Finding 7 of this report.



Key takeaways

- > Women with intellectual disabilities and women with psychosocial disabilities are disproportionately subject to forced or coerced reproductive practices, depriving them of their ability to get and stay pregnant.
- > Measures of reproductive control against women with disabilities not only invalidate their will and preferences, but they also increase women's vulnerability to sexual abuse.

Finding 4: Women with intellectual disabilities and women with psychosocial disabilities face numerous restrictions on their right to make decisions about parenthood.



Laia is a 24-year-old woman with an intellectual disability who lives in Spain. Laia has three children, and she felt judged by the healthcare staff during her last pregnancy, as they made assumptions about her ability to be a mother of three kids. “When I was pregnant with my third child, the midwife asked me, ‘Why don’t you have an abortion?’ She told me that I already had two young children, and things would be hard for me with a third. She told me there were abortion methods. I told her no, that I got pregnant because I wanted to.”

Many women with disabilities can relate to Laia’s experience of being questioned or judged by healthcare providers—and society in general—about their decisions regarding having children. While women without disabilities are frequently pressured by society to want and prioritize motherhood, women with disabilities still must advocate for their right to decide to have children.

Restrictions on decisions about if, when, and how many children to have

All women with disabilities, including those with intellectual disabilities and those with psychosocial disabilities, have the right to exercise their legal capacity in the context of parenthood by making their own decisions about the number and spacing of their children.⁷³ Moreover, they have the right to receive the support they require—and wish to receive—to make family planning decisions, from accessible information to disability-inclusive sexual and reproductive health services.⁷⁴

Article 23 of the CRPD, Respect for home and the family, demonstrates how central the right to legal capacity is to parenthood, as it refers to both:

- > The free and full consent of the intending spouses to found a family; and
- > The right to decide freely and responsibly on the number and spacing of children.

In spite of that, many women we talked to shared that they had been told by family members that they were not allowed to have children.

“ My dream was always to have a baby, but my mother still doesn’t think I’m ready. So, I’m not going to do it.”

– A woman with an intellectual disability in the United States

“ My mother won’t allow me to have children. It doesn’t really affect me because she has always been making the decisions for me ever since birth.”

– A woman with a psychosocial disability in Fiji

Beyond individual family members or healthcare providers—like in Laia’s case—women in the field research also spoke to how society as a whole pressures them against having children.

“ In traditional settings, they have a mentality that you can’t get married or have children if you have psychosocial disabilities.”

– A woman with a psychosocial disability in Uganda

“ The community...my relatives—they said they shouldn’t allow me to have kids...I heard it, I felt bad, I felt embarrassed, and I felt low...”

– A woman with a psychosocial disability in Uganda

“ [People said] having children would ruin my life and that I should not have children due to my disability.”

– A woman with an intellectual disability in Spain

Restrictions on decisions about parenting

Even when women with disabilities do have children, they may be denied the right to make their own parenting decisions.

“ My parents make most of the decisions [about my child’s healthcare], but sometimes I can take my child to the hospital by myself.”

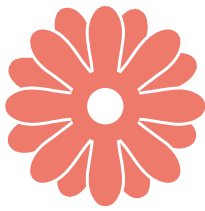
– A woman with a psychosocial disability in Fiji

This interference in the parental decision-making of women with disabilities can rise to the level that parental rights are permanently terminated. Many women with disabilities justifiably fear that child protective services will remove their children based on the fact that they are a parent with a disability or have a guardian.⁷⁵ The CRPD Committee has made clear: Disability, mental capacity, guardianship status, and the use of support in decision-making should never be used as reasons to deny parental rights.⁷⁶ However, some custody laws around the world continue to consider these factors when deciding to terminate parental rights.⁷⁷

As a result, mothers with disabilities disproportionately face child custody cases and lose custody of their children.⁷⁸ These custody decisions can cause both generational and immediate harm, as two women who took part in the field research spoke about:



Kelly, a young woman with an intellectual disability in the United States, told us that her biological mother is also a woman with disabilities. Kelly explained that when she was a baby, her mother was determined by a court to be an “unfit mother” because of those disabilities, and that she subsequently lost custody of Kelly and her brother. As a result, Kelly was adopted by her aunt, and her brother ended up in the foster care system. In Kelly’s words, “I was in a better outcome, but for my brother, he’s in a bad outcome.”



Ariadna, a woman with a psychosocial disability in Fiji, described her own experience with child custody decisions. She shared, "My ex-husband threatened to tell the social welfare authorities that my children are not safe with me because of my disability and that they should go to his family. He used this in court to take away one of my children. I felt helpless and hopeless."



Key takeaways

- > Women with disabilities face many barriers to exercising their right to freely decide if, when, and how many children to have.
- > Denials of legal capacity negatively affect both women's decision to have children and women's ability to retain custody of their children.

Finding 5: Women with intellectual disabilities and women with psychosocial disabilities are deprived of the right to make their own decisions about marriage.



Daniela is a woman with an intellectual disability who dreams about getting married. “If I could, I would get married. But some people tell me I can’t.” Daniela is under a guardianship regime that explicitly revokes the right to marry. Although Spain abolished guardianship systems in 2021, Daniela was still waiting for a judge to review her case at the time of the field research. While explaining this, she cried and said, “If I want to [get married], why can someone else tell me I can’t?”

Daniela is not alone. Many countries have laws that deny the right to marry on the grounds of disability.⁷⁹ In other countries, although legislation does not explicitly deny the right to marry, women with intellectual disabilities and women with psychosocial disabilities are prevented from making their own decisions about marriage.

Laws that deny free decision-making about marriage

The CRPD enshrines the right of all persons with disabilities to exercise their legal capacity to make their own decisions—with support if and when desired—about getting married.⁸⁰ However, cases like Daniela’s reveal the difficult and common reality that, around the world, many women with intellectual disabilities and women with psychosocial disabilities are denied the legal right to marry.⁸¹

Often, this legislation explicitly denies persons with disabilities the right to marry. This type of law frequently uses the decision-making skills of a person (the controversial concept known as mental capacity) as the justification for doing so.⁸² However, this argument—and the laws based upon it—violate the right to legal capacity, as legal capacity is inherent in all persons.⁸³ Indeed, the CRPD Committee has made clear that recognition of a person’s legal capacity should not relate to or be contingent upon mental capacity.⁸⁴

Other legislation that prevents women with intellectual disabilities and women with psychosocial disabilities from freely making decisions about marriage are laws related to social benefits.⁸⁵ Often, legislation that defines who is eligible to receive certain social benefits—such as financial support or low-cost healthcare—includes a maximum joint income that married couples can earn. Beyond this joint-income level, each spouse will be disqualified from receiving benefits.

In practice, many persons with disabilities choose not to get married—even when they wish to do so—to avoid losing eligibility for life-saving social benefits. This reality has led many to refer to these regulations as “marriage penalties.”⁸⁶ Multiple women who took part in the field research spoke about these marriage penalties and how these regulations negatively influenced their free decision-making.

“ I would like to get married, but I asked [the local government] and they told me that I would lose my [disability-related] pension, because the other person [partner] is supposed to be able to support me financially.”
– A woman with an intellectual disability in Spain

“ No [I would not get married]. Because they [the government] would take my money away.”
– A woman with an intellectual disability in Spain

“ Everyone in my life would be supportive [of me getting married]. The only problem I would have is Medicaid and SSI benefits [social benefits] obviously, because that’s what I’m on now...”
– A woman with an intellectual disability in the United States

Informal practices that deny free decision-making about marriage

Even when there are no laws in place that limit the right to marry, women with intellectual disabilities and women with psychosocial disabilities still face *de facto* denials of the right to make their own decisions about marriage.

We heard from many women that their family members had openly prohibited them from getting married or pressured them against doing so.

A woman with an intellectual disability in Kenya shared how her mother has stopped her from getting married, explaining that “she just refuses.”

“ **My mom said that it’s not a good idea for me to have a husband because it will be stressful.**”

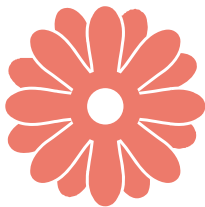
– A woman with a psychosocial disability in Fiji

Others were prevented from making their own decisions about marriage because of strict rules in institutional settings that prohibited residents from being married. The connections between institutionalization and legal capacity violations in the context of SRHR are further discussed in Finding 6.

“ **I would love to get married...[but] I can’t get married in a group home.**”

– A woman with an intellectual disability in the United States

Some women shared that they were pressured not to get married based on the sexist beliefs of who an ideal wife is—someone whose predominant value in a marriage is through care and other home-based work.⁸⁷ For example,



Alma is a woman with an intellectual disability and a wheelchair user who lives in Spain. She is 25 years old and dreams about getting married. When she shares these dreams, she is questioned by others and has internalized these prejudices. "People asked me, 'How can you get married? Do you know how to cook? Can you take a shower by yourself?' I think about it, and they are right." Her mother is also against Alma getting married because her partner also identifies as a person with a disability. This has influenced Alma's decision about marriage. Resignedly, she shared, "It is my dream to get married, but my partner also has a disability...two disabilities together are not a match. My mother tells me I need to find a proper man."

Decision-making about marriage and the dignity of risk

Denying women with intellectual disabilities and women with psychosocial disabilities the right to make decisions about marriage, whether through a formal substitute decision-making regime or informally, denies women the dignity of risk. The dignity of risk is the idea that all persons—including those with disabilities—should be given the opportunity to make decisions in life, even when those decisions come with a risk of negative consequences.⁸⁸ This concept is grounded upon the idea that taking risks and responding to any consequences that follow is a natural part of life, one that is essential for dignity, learning, and growth.⁸⁹ While the dignity of risk applies to many of the decisions discussed in this report, marriage is a helpful context in which to understand the concept.

Women with disabilities are regularly denied the dignity of risk in this context because others want to shield them from experiencing (what can be) life-altering negative outcomes when marriages go poorly. But whenever anyone decides to get married, there is risk. Choosing to get married is an impactful life decision that can (and often does) come with substantial and painful consequences. Some thrive in their marriages. Others get hurt, heartbroken, or taken advantage of. And yet, people choose to take this significant step every day. Women with intellectual disabilities and women with psychosocial disabilities want and deserve the same opportunity.



Key takeaways

- > Regardless of there being a formal substitute decision-making regime in place, many women with intellectual disabilities and women with psychosocial disabilities are denied the right to make their own decisions about marriage.
- > Having the opportunity to take risks when making decisions, including those about marriage, is a central part of life. It is essential for dignity, learning, and growth.

Finding 6: Institutionalization fuels legal capacity violations in the sexual and reproductive health and rights context.

Denial of legal capacity is inherent to institutionalization. Detainment in an institution is not only a human rights violation in itself, but it is also inextricably linked to legal capacity violations—both in the institutionalization process and during the time spent in the institution.⁹⁰

This connection is evident in several defining elements of life in institutions:⁹¹

- > There is a lack of control over day-to-day decisions.
- > There is a lack of choice over with whom to live or with whom to socialize.
- > Rigid routines are imposed, ignoring people’s will and preferences.
- > A paternalistic approach is used.
- > There are entrenched gender norms.

More than a particular setting or size, an institutionalized setting is a place of residence where a person loses their personal choice and autonomy. Institutional settings include but are not limited to, psychiatric institutions, long-stay hospitals, special boarding schools, nursing homes, sheltered or protected living homes, and group homes.⁹²

Women with disabilities around the world are isolated and forced to live in institutions,⁹³ and women with intellectual disabilities and women with psychosocial disabilities are especially at risk of institutionalization.⁹⁴ Those under guardianship are more likely to be institutionalized than those not under guardianship.⁹⁵

As the CRPD emphasizes, institutionalization must never be considered a choice.⁹⁶ And when the right to live in the community—guaranteed in Article 19 of the CRPD—is not respected, widespread denials of decision-making often follow, as addressed later in this section.

Numerous women who participated in the field research had previously been institutionalized, and many were still institutionalized at the time of the research. Several women with psychosocial disabilities shared that they had been detained in long-stay hospitals, while many women with intellectual disabilities reported being forced to live in either large institutions or group homes.

“ My family grabbed me, forced me into a taxi. I stayed there [a psychiatric hospital] for one month. I couldn't leave even though I wanted to. I've been admitted three times. Either my parents or my elder brother decides [to send me]. I told them I didn't want to go.”

– A woman with a psychosocial disability in Fiji

“ I was sent to an institution. I didn't want to, but this is not like, 'If I don't want to, I don't go.' Can someone force you to be in a place where you don't want to be? And there I am.”

– A woman with an intellectual disability in Spain

Traditional gender and sexuality norms and institutionalization

Historically, women have been institutionalized for patriarchal reasons, such as failure to conform to traditional female gender norms.⁹⁷ In the past, this nonconformity was often labeled as hysteria, which then served as a justification for institutionalization.⁹⁸ The connection between gender and institutionalization can still be seen today, such as when women are institutionalized after questioning the authority of their husbands⁹⁹ or at the request of their spouses after seeking divorce.¹⁰⁰

The LGBTQIA+ community has also long been a target of institutionalization. For example, some institutions exist to force “conversion therapy” upon the people living there. This harmful and discredited practice is premised on the belief that a person's sexual orientation or gender identity can and should be changed when their sexual orientation or gender identity does not align with the prevailing social norm.¹⁰¹ Under this homophobic and transphobic justification, LGBTQIA+ persons are disproportionately placed in institutions.¹⁰²

People whose sexuality or sexual and reproductive health choices do not align with community or family norms face unique challenges regarding institutionalization. For example, some women who took part in the field research shared how institutionalization can be used as a threat to deny the decision-making of persons with disabilities from the LGBTQIA+ community. At the same time, the intersection of disability and diverse sexual orientation can be used to justify institutionalization.

For example,



Nihola is a 39-year-old woman with a psychosocial disability in Fiji. She developed feelings for another woman who went to her church. When other church members found out, they called the police, and Nihola was involuntarily admitted to a psychiatric hospital. Nihola explained, "My mom and dad stopped me from liking anyone. They said they would call [a psychiatric hospital], and I would be sent back there if I liked someone. It was bad at [the psychiatric hospital]. I was there for three weeks."

Similar to Nihola's experience, women with diverse sexual orientations living in institutions said they also noticed attempts of staff and others to limit their decision-making related to their sexuality and intimate relationships.

“ In the center [institution] where I live, some housemates and staff do not respect my girlfriend, and I really like her. No one knows what I go through and the barriers I face. I'm in love with her. I won't break up with her just because some people don't want me to be with her, kiss her...They don't want me to choose.”

– A woman with an intellectual disability in Spain

Increased risk of SRHR-related violations in institutions

Institutionalization can increase the risk of sexual and reproductive health-related legal capacity violations, such as:

- > [Forced sterilization, forced abortion, and forced contraception](#),¹⁰³
- > [The denial of the right to marry](#),¹⁰⁴ and
- > [The denial of the right to found a family](#).¹⁰⁵



Examples of each one of these violations in institutional settings are included in the previous findings. **Do you want to go back and read them again?** Just click on the hyperlinks.

In institutional environments, these violations are not only permitted, but they are often codified in internal rules. Many of the women we spoke with talked about the strict rules they were subject to related to dating, getting married, and having children in the institutional settings in which they lived. These rules prevented them from exercising their legal capacity in decisions related to marriage and parenthood so long as they remained in an institutional setting.

“ I would love to get married...[but] I can't get married in a group home, and [my mom] doesn't think I can handle my own apartment. I would love to; my dream was always that.”

– A woman with an intellectual disability in the United States

“ I was told that if I get pregnant living in the center [institution], my child may be taken away from me. To get pregnant, first, I need a job, a house, a stable life, and to live with my partner by ourselves.”

– A woman with an intellectual disability in Spain

Restricted opportunities for socialization and relationships

Numerous women who took part in the field research talked about institutions' strict rules regarding visits and curfews, which prohibited partners from entering their room—or in some cases, even the house. Rules such as these are common in institutions and have the effect of policing and controlling women's decision-making regarding having private and intimate time with their partners.¹⁰⁶ These restrictions interfere in if, when, and where to have these private moments.

“ They have rules about [dating], like I'm only allowed out four hours a day, and only if my mom says yes to the guy. And he can't even come in and see my room, so...”

– A woman with an intellectual disability who lives in a group home in the United States

Heightened discrimination against older women with disabilities

Many older women with disabilities living in institutions are also denied the possibility of having private time with their partners, and these violations likely receive even less attention when they impact older women than they do when they impact younger women living in institutions. This is because older women—with and without disabilities—face stereotypes that they are undesirable and asexual, with no need or want for intimacy, when compared to younger peers.¹⁰⁷

A 65-year-old woman with an intellectual disability in Spain shared that she has a partner who lives in the same institution as she does, but that they are not allowed in each other's rooms. “It makes me sad”, she said.



Key takeaways

- > Institutionalization is a systemic rights violation that inherently denies decision-making and leads to many other human rights violations. To combat these human rights violations, institutions must be closed, not reformed.
- > Legal capacity violations, particularly those relating to gender norms and sexuality, are inherent to institutionalized settings. Institutions have coercive, punitive, and dehumanizing practices that act to control the sexual and reproductive decision-making of those in institutions. These rules prevent persons with disabilities from exercising their legal capacity.
- > Some groups, such as women with diverse sexual orientations and older women, experience multiple and intersecting forms of discrimination in the context of SRHR-related legal capacity violations in institutions.

Finding 7: Gender-based violence can be both a cause and a consequence of legal capacity violations.

For women with intellectual disabilities and women with psychosocial disabilities, the relationship between legal capacity violations relating to SRHR and gender-based violence (GBV) is inextricable. In each of the five focal countries, field research participants spoke about GBV experiences that were directly related to their SRHR decision-making and denials of their legal capacity.

GBV refers to acts of violence perpetrated against women and gender-diverse persons on the basis of their gender.¹⁰⁸ This gross human rights violation includes multiple forms of violence,¹⁰⁹ such as physical, emotional, psychological, sexual, and economic violence. Women with disabilities may experience the same forms of GBV that those without disabilities are subject to, as well as forms that uniquely or disproportionately impact women with disabilities. These include:¹¹⁰

- > Violence perpetrated by a caregiver;
- > Withholding of medication or an assistive device;
- > Denial of basic needs, such as food or toileting;
- > Restriction of communication devices;
- > Forced or coerced medical procedures; and
- > Enforced isolation.

The connections between denials of legal capacity, GBV, and SRHR are numerous.

Legal capacity violations as a form of GBV

Certain legal capacity violations, such as forced sterilization, forced abortion, and forced contraception, are considered to be acts of GBV,¹¹¹ as addressed in Finding 3. Indeed, the violence of forced sterilization and abortion is so severe that these practices are recognized by the United Nations as a form of cruel, inhuman, or degrading treatment, and in some cases, torture.¹¹²



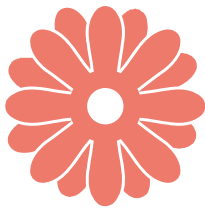
Ariadna, a woman with a psychosocial disability in Fiji, experienced this type of violence when doctors did not seek her free and informed consent before performing a sterilization procedure right after she gave birth. "The doctors didn't discuss any other options. [...] After I recovered and I felt more like myself, I realized I didn't want that surgery."

GBV as a form of legal capacity violation

Because control is often a dominant element in GBV, especially in intimate partner violence, these acts of violence often include legal capacity violations. Women who took part in the research spoke about how abusive partners regularly disrespect the sexual autonomy and decision-making of women with disabilities, a type of GBV. These are also legal capacity violations, as they deny women the right to make decisions about their lives and to have those decisions respected. For example,



Katherine is a 25-year-old woman with an intellectual disability in the United States who has been in several unhealthy relationships. Katherine shared that those former partners disrespected her decisions about sex. She wanted to wait to have sex until she was married, "...but I had people talk me into things or take advantage of me."



Kissa is a 26-year-old woman with a psychosocial disability in Uganda who was in a relationship in which her decision-making was constantly manipulated. Her partner would influence her decisions by making her feel that she was wrong, and that he was always right. As a result, she was pressured to base her decisions on what he wanted her to do. "He was manipulative. This made me lose my self-esteem."

Lack of SRHR information contributes to GBV

Control over women's access to SRHR information limits the exercise of free and informed decision-making, as discussed in Finding 2. It can also contribute to GBV. A lack of comprehensive information about SRHR and GBV—which includes critical information about consent and bodily autonomy—is known to increase vulnerability to GBV.¹¹³

“ My first exposure to sex was through my abuse. I was abused as a child. It was only when I was 19 that I understood that what happened was not right.”
– A woman with a psychosocial disability in Fiji

The impact of GBV on future decision-making

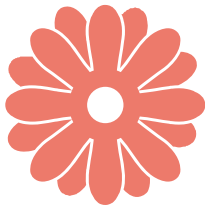
GBV can also negatively impact the survivors' future SRHR-related decision-making. Sometimes, this is a result of long-term trauma caused by GBV. For example,



Paula is a 57-year-old woman with an intellectual disability in Spain, who shared how she experienced gender-based violence from two of her former partners. Her last partner was both physically and psychologically violent. She mentioned having decided not to date anyone anymore due to these negative experiences. "I don't want to date anyone anymore. I can't understand why a guy hits you. Your partner who loves you. I don't get it. And I will never forget." Later, Paula added, "I don't want to have kids or relationships. I've had many relationships and have no luck with men. I'm better off alone, without having to deal with men."

Cascading violations

When women with disabilities experience GBV, increased outside control over their SRHR decision-making can follow. Instead of protecting survivors with disabilities against future harm, this overprotection exacerbates the harm and leads to additional human rights violations. Daniela's experience with GBV and forced sterilization is an example of this painful cycle:



Daniela is a woman with an intellectual disability who lives in Spain. She was coerced into agreeing to sterilization after a rape. "I had surgery for that because, when I was 20 years old, a guy saw me at a subway station, followed me, and took me to a building and...I didn't want [the sterilization], but to obey my mother, I had to do it." After the surgery, Daniela never saw a gynecologist again.

Daniela's story demonstrates how GBV can be both a cause and a consequence of legal capacity violations. After experiencing sexual violence, Daniela was denied her right to legal capacity when she was coerced into sterilization—another form of GBV. Following her sterilization, Daniela was further prevented from accessing and making decisions about her sexual and reproductive healthcare. Her experience exemplifies the connection between GBV, the denial of legal capacity in the context of SRHR, and the cascading effect of human rights violations.



Key takeaways

- > Gender-based violence can be both a cause and a consequence of legal capacity violations when making decisions about sexual and reproductive health and rights.
- > The connections between legal capacity violations, gender-based violence, and SRHR take many forms, including forced procedures to control women's reproductive lives and coercion over decision-making in intimate relationships.

Country-Specific Findings

This section documents the findings of the field research in Fiji, Kenya, Spain, Uganda, and the United States that are specific to each of those countries. These findings are included here rather than in the Global Findings because, although crucial, they were not observed across multiple countries. These findings also reflect distinct cultural contexts, in which people's experiences are shaped by—among other things—specific societal understandings of gender and disability.

Fiji

The research in Fiji was led by PSA and focused on women with psychosocial disabilities. It was conducted in three locations:

- > Lautoka, in the Western Division of the island of Viti Levu, Fiji's largest island;
- > Suva, Fiji's capital, located in the Central Division on the southern coast of Viti Levu; and
- > The island of Lakeba, in the Lau Province, a remote area located approximately 300km from Viti Levu.

Fijian law continues to allow substitute-decision making regimes that deny the legal capacity of women with disabilities and negatively impact SRHR decision-making. For example, the Mental Health Act (2010) permits forced institutionalization and forced medical treatment of persons with psychosocial disabilities.¹¹⁴ In addition, informal legal capacity violations are frequent in the country.

Location is a critical factor in how women in Fiji get access to SRHR information. For example, access to services and information related to SRHR—crucial to support the exercise of legal capacity—was very limited among the women on Lakeba. Geographic inequalities must also be considered when working to ensure the effective implementation of the right to legal capacity in the SRHR context.

Moreover, some of the women who participated in focus groups or interviews shared that they did not think their psychosocial disability had an impact on the informal legal capacity violations they experienced. Rather, they felt that they were not allowed to make their own decisions because they were women in Fijian culture. Gender plays a crucial role in the way in which many women with psychosocial disabilities are treated in Fiji (and around the world). Multiple women we spoke to in Fiji mentioned how their brothers were responsible for making decisions for them.

Country-Specific Findings

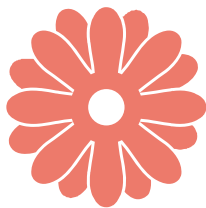
However, disability also undeniably impacts women with psychosocial disabilities' chances of exercising their right to legal capacity, as their testimonies show. Women described experiencing restrictions on their freedom to exercise their own legal capacity because of how others perceived their psychosocial disabilities.

For example:

- > Being judged by healthcare providers because of disability when seeking sexual and reproductive healthcare

“ I do ask questions [during medical appointments], but sometimes I hesitate because some doctors judge me due to my psychosocial disability.”

- > Not being allowed to be in a relationship because of disability



Vina, a 53-year-old woman with a psychosocial disability who lives in Fiji, used to want to be in a relationship, but her family told her she was not allowed to do so. I have had the desire [to be in a relationship], but my mom says no because of my disability and in case a boyfriend abuses me.”

The fact that some participants felt that gender was the primary explanation for the legal capacity violations they experienced highlights the importance of addressing intersectionality when developing social, policy, and legal responses to violations of the right to legal capacity.

 Kenya

The research in Kenya was led by KAIH and focused on women with intellectual disabilities. The research was conducted in three locations:

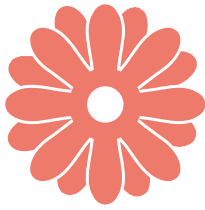
- > Nairobi, the populous, urban Kenyan capital;
- > Machakos, the small city of a rural county close to Nairobi; and
- > Nakuru, the large capital city of a majority rural county.

Guardianship and other substitute decision-making regimes are still legal in Kenya.¹¹⁵ However, across all three locations, women most often reported experiencing informal denials of their SRHR decision-making.

In some cases, experiences differed by location. In Machakos and Nakuru, the more rural areas, women were uncomfortable answering questions about LGBTQIA+ identities and relationships, and one woman shared that she had never heard of the topic. Those who had heard of LGBTQIA+ identities and relationships said little in response to these questions, because—from the perspective of one of the Kenyan researchers—the heavy religious influence and the frequent targeting, bullying, and killing of LGBTQIA+ Kenyan persons in these regions have made participants afraid to speak about these topics, let alone explore and make decisions in alignment with those identities. As the researcher explained, if anyone in the groups identified in this way, she doubted that they would ever voice it in front of others.

Across locations, some women in the field research shared experiences of financial dependence upon their families and isolation from the community. While people in many communities (in Kenya and beyond) are expected to contribute financially to family with whom they're living, the combination of isolation and financial dependence experienced by many women with intellectual disabilities made it difficult for them to disobey what their families told them to do about relationships and marriage.

Country-Specific Findings



Annitah is a 50-year-old woman with an intellectual disability from Kenya. Annitah shared that she would love to be married, but that her family wants to make all her decisions for her—particularly decisions about relationships. While other women might be able to ignore their family’s opinion and make their own independent decisions, Annitah cannot. She has no meaningful opportunity to date or find a partner, because she is financially dependent upon her family, and they prevent her from going out into the community. She explained, “When we get our own money, parents take it from us, they don’t want us to be independent. They tell you that you don’t know how to use the money. They don’t want us to be with our own money... I’m 50 years old, but I’m only allowed to leave the house to go to work.”



Spain

The research in Spain was led by Liber and focused on women with intellectual disabilities. It was conducted in two locations:

- > Madrid, the capital of the country and its largest city; and
- > Seville, a major city in the South of the country.

Spain has recently abolished many laws that violated the legal capacity of persons with disabilities. For example, Spain prohibited any type of sterilization that is not based on informed consent in 2020.¹¹⁶ The following year, Spain abolished guardianship—although it still allows substitute decision-making in some circumstances, such as for healthcare or financial decisions of persons who are considered by the law to be in need of mandatory support for decision-making—and passed a law on supported decision-making for persons with disabilities.¹¹⁷

The progress in legislation, although welcomed by the disability community—who advocated for these reforms for decades—does not seem to have improved the lives of women with intellectual disabilities in the country yet. Many of the participants in the field research were aware of the change in legislation. Still, none of them reported having had more opportunities or having felt more supported to make their own decisions after the legal reforms than they had before. According to the researchers in the country, this is due to two main factors:

- > The change in legislation is recent; and
- > The new law was not accompanied by a social paradigm shift.

Women's experiences of legal capacity violations in Spain also intersect with care work. Some of the women we talked to described being questioned when they made the decision to have children, while at the same time being expected to perform care work duties for their families. Intriguingly, the same family members who often question the skills of the women we talked to as parents concurrently demand their skills as caregivers of children, such as siblings.

Country-Specific Findings

For example,



Laia is a woman with an intellectual disability in Spain. She is married and is the mother of three children. She shared how unsupportive her mother was of her decision, trying to prevent her decision-making related to marriage and having children. "When I was 19, I left home to be with my husband. As I have a disability, my mother called the police and said someone should check my mental capacity. She didn't want me to leave because I have four siblings and used to take care of the younger ones. She would lose a caregiver. How can anyone tell me who to live my life with?"

When a woman with an intellectual disability in Spain got pregnant, she told her mother she would have the baby and leave home to be with the baby's father. The mother's reaction made the woman regret the pregnancy, although she wanted to be a mother. "[My mother] said I could have an abortion; I could do other things [besides having the baby]. But I said no. [My mother said,] 'Oh my God, how come? You are so easy. You are going to leave me alone with your six siblings. You are the only one who helps me. You have no right.'"

Country-Specific Findings

Uganda

The research in Uganda was led by TRIUMPH and focused on women with psychosocial disabilities. The research was conducted in Jinja, a city in southeastern Uganda with a population of about 300,000 people, as well as in surrounding rural areas.

Even with the passage of the highly anticipated Mental Health Act (2018)¹¹⁸, systems of substitute decision-making are still legal and common in Uganda—in fact, almost all the women who participated in the research reported having guardians.

Most women—across urban and rural settings—had previously had or currently have all healthcare decisions made for them by a guardian. Of the women who now have some control over their own healthcare decision-making, several reported that traumatic experiences in healthcare settings discouraged them from deciding to visit a gynecologist again.



When Kissa, a 26 year-old-woman with a psychosocial disability in Uganda, was asked about how often she accesses sexual and reproductive healthcare, she shared, “I don’t [go to the gynecologist] because I had a traumatic experience with a gynecologist...I asked questions, but they were not answered. I was told to shut up and not ask a lot of questions and go do what they told me to do...I believe [a] first impression lasts, so I would only check with the gynecologist if I experience a crisis or an emergency case.”

The United States

The field research in the United States was led by SABE and focused on women with intellectual disabilities. The research took place in Cincinnati, Ohio, which has a population of over 300,000 people. Ohio is in the midwestern United States.

Guardianship over adults with disabilities is still permitted under Ohio law.¹¹⁹ Unlike some other U.S. states, Ohio does not yet have any laws that formally recognize alternatives to guardianship, like supported decision-making.¹²⁰

Women of color with intellectual disabilities—and in particular, Black, Indigenous, and Latina women with intellectual disabilities—living in the United States have faced denials of their legal capacity in the context of SRHR decision-making for generations.¹²¹ These violations are grounded in systemic and interpersonal racism, and they have often taken the form of forced sterilization, contraception, and abortion. These violations against women of color continue today, as we heard from one of the women who participated in the field research:



Ashley is a middle-aged woman of color with an intellectual disability from the United States, and she has a guardian. Ashley's guardian is not a family member or friend. Instead, her guardian is someone appointed by the court.

Ashley explained that, after years of being told by her guardian to take injection birth control, she is now "too old to have a baby." She shared that she would have loved to have had children, and that she thought she could have done so if she had been given the opportunity at an earlier time in her life. In addition to being made to take contraception by her guardian, Ashley said that, over the course of her adult life, she has been told "many times" by her guardian and others that she should not have children. "I feel bad [about that]," she shared.

Recommendations

Ending legal capacity violations in the context of sexual and reproductive health and rights requires collaboration and active engagement of many actors. Therefore, the recommendations proposed below are specifically targeted at the actors who have a key role in combating legal capacity violations. They are:

- > Law and policymakers
- > Sexual and reproductive healthcare providers
- > Families and others providing support to women and gender-diverse persons with disabilities
- > Sexual and reproductive rights organizations
- > Organizations of persons with disabilities

These recommendations are an invitation to these stakeholders to work collaboratively to ensure the full realization of the right to legal capacity in the context of SRHR for women and gender-diverse persons with intellectual disabilities and women and gender-diverse persons with psychosocial disabilities.





To law and policymakers:

- > Repeal any legislation that allows substitute decision-making in any of its forms or that allows any other form of violation of Article 12 of the Convention on the Rights of Persons with Disabilities. This includes abolishing guardianship and conservatorship regimes and any legal provisions that override a person's will and preferences in the context of exercising their rights.
- > Repeal any legislation that applies the best interests framework to persons over 18 years old on the grounds of disability.
- > Repeal any legislation that allows forced reproductive practices, such as sterilization, abortion, and contraception, without respecting a person's will and preferences and their free and informed consent.
- > Repeal any legislation and dismantle any legal, funding, or administrative framework that allows for the existence of institutions or institution-like settings (such as group homes, social care institutions, or segregated housing) and any other places that intrinsically deny or limit the legal capacity, autonomy, and decision-making rights of persons with disabilities.
- > Enact and enforce laws on supported decision-making or similar models, especially in the context of SRHR, that establish quality standards and include budget allocations for implementation.
- > Enact and enforce laws that guarantee accessible and comprehensive sexuality education for persons with disabilities, ensuring sufficient budget allocations for effective implementation.
- > Enact and enforce accountability and monitoring and evaluation mechanisms to ensure that legal reforms have a meaningful and long-lasting impact on advancing the right to legal capacity.
- > Allocate funds to provide training led by persons with disabilities and their representative organizations on how to support decision-making in the context of SRHR to a series of stakeholders. Trainings must be grounded upon a human rights framework and address structural and contextual barriers that prevent the exercise of legal capacity of women and gender-diverse persons with disabilities, such as ableism, patriarchy, racism and white supremacy, homophobia, ageism, power dynamics, and poverty.

To law and policymakers (Cont.)

- > Allocate funds for data collection on the exercise and denial of legal capacity in the context of sexual and reproductive decision-making, ensuring the gathering of disaggregated data—for example, by type of disability, race and ethnicity, gender identity, sexual orientation, age, class, and geographic location.
- > Allocate funds to ensure all the abovementioned measures are effectively implemented in both urban and rural areas and within groups of persons with disabilities who experience multiple and intersecting forms of discrimination due to other identities, such as race and ethnicity, gender identity, sexual orientation, age, class, or geographic location.
- > Closely consult with, compensate, and actively engage women and gender-diverse persons with disabilities and their representative organizations in the design and enforcement of all laws and policies related to legal capacity and sexual and reproductive decision-making.



To families and others providing support to women and gender-diverse persons with disabilities:

- > Provide support by actively listening, validating the person's choices, and asking what role (if any) they would like you to play in their decision-making process. Respect the person's decision even when you disagree or when they have decided not to receive support in their decision-making.
- > Ensure the person with a disability remains in control and at the center of the SRHR decision-making. Ensure this by 1) facilitating access to comprehensive, balanced, and accessible SRHR information and to supported decision-making tools; 2) supporting the person in navigating SRHR systems when requested; and 3) advocating alongside the person if their rights are denied.
- > Participate in trainings^{xiv} led by women and gender-diverse persons with disabilities on supported decision-making, especially in the SRHR context. In doing so, reflect on internalized beliefs or assumptions about disability, legal capacity, and SRHR.
- > Work collaboratively with organizations of persons with disabilities and sexual and reproductive rights organizations to advance the right to legal capacity in the SRHR context by developing a shared understanding and dialogue grounded in trust, respect, and autonomy of women and gender-diverse persons with disabilities.

^{xiv} All training must be grounded upon a human rights framework and address structural and contextual barriers that prevent the exercise of legal capacity of women and gender-diverse persons with disabilities, such as ableism, patriarchy, racism and white supremacy, homophobia, ageism, power dynamics, and poverty.



To sexual and reproductive healthcare providers:

- > Ensure women and gender-diverse persons with intellectual disabilities and women and gender-diverse persons with psychosocial disabilities are at the center of decision-making and access to information. When attending to them, always speak directly to them, ask them any questions related to their health and decisions, and provide accessible and human rights-based SRHR information.
- > Offer quality and unbiased healthcare attention to women and gender-diverse persons with disabilities. Actively challenge diagnostic bias and risk-based assumptions that may lead to disregard for will and preferences or substitute decision-making of women with disabilities. Understand that differing communication styles or accessibility needs, experiencing emotional distress, or psychiatric diagnosis do not negate a person's right to bodily autonomy and SRHR decision-making.
- > Always seek women and gender-diverse persons with disabilities' free and informed consent for treatments and procedures, ensuring they understand their options and are empowered to express their will and preferences.
- > Ask each person if and what kind of support they want to receive when receiving SRH care. Do not assume that all persons with intellectual or psychosocial disabilities have the same accessibility and support needs. Where requested, allow a support person (such as a trusted peer, friend, or family member) to accompany the person with a disability through appointments and procedures and to provide support. In doing so, always center the voice of the person with an intellectual or psychosocial disability, not the support person.
- > Apply trauma-informed principles to your interactions when providing services by developing trust, upholding rights, offering choices, and asking the person with a disability what makes them feel safe and respected.
- > Establish accessible and responsive complaint/grievance redressal mechanisms within SRHR facilities for women and gender-diverse persons with disabilities to raise concerns without any fear or apprehension; engage them and their representative organizations in designing and monitoring these systems to ensure they are rights-based and user-friendly.

To sexual and reproductive healthcare providers (Cont.):

- > Establish partnerships and make referrals to community healing circles, or accessible safe spaces, particularly for persons facing violence, medication-related trauma, or breakdowns in support systems. When a person discloses distress or crisis, offer to connect them with trusted community-based alternatives.
- > Participate in trainings led by women and gender-diverse persons with disabilities on a range of topics related to disability and gender rights and justice, including legal capacity, supported decision-making, bodily autonomy, provision of accessible information, alternative methods of communication, and informed consent. Commit to ongoing learning on these topics, reviewing new resources as they emerge.



To sexual and reproductive rights organizations:

- > Center legal capacity as a crucial issue in the sexual and reproductive health and rights agenda. Without the effective implementation of the right to legal capacity, SRHR and bodily autonomy will not be guaranteed to all.
- > Engage women and gender-diverse persons with disabilities in your work in an inclusive, accessible, and meaningful way. Closely consult with them for the best strategies to ensure meaningful inclusion and use tools they have created as references for how to do so (such as the [Listen Include Respect Guidelines](#) and the [Guidelines for making events and activities \(in person and online\) inclusive and accessible for persons with psychosocial disabilities](#)).
- > Assess internal bias related to disability and implement measures to combat harmful stereotypes against women and gender-diverse persons with disabilities. In doing so, recognize and reckon with the multiple and intersecting forms of discrimination faced by many persons with disabilities due to other identities, such as race and ethnicity, gender identity, sexual orientation, age, class, or geographic location.
- > Address the specific barriers faced by persons with intellectual disabilities and persons with psychosocial disabilities when accessing SRHR services, such as exclusion, gatekeeping of information, and traumatic histories of coercion that can undermine autonomy in the SRHR context and prevent their engagement with SRHR services.
- > Develop internal accountability processes to assess and improve organizational practices related to disability inclusion and justice.



To organizations of persons with disabilities:

- > Center sexual and reproductive health and rights as a crucial issue in legal capacity discussions and advocacy and strengthen organizational capacity on SRHR, legal capacity, and intersectionality. Recognize that the effective implementation of the right to legal capacity requires ensuring bodily autonomy and SRHR decision-making and incorporate SRHR as a core part of advocacy efforts.
- > Develop and disseminate tools for supported decision-making that are responsive to community needs and to the cultural context(s) in which you work.
- > Promote the leadership of women and gender-diverse persons with disabilities—especially those with psychosocial disabilities and those with intellectual disabilities—within your organization. Center those who face multiple and intersecting forms of discrimination due to other identities, such as race and ethnicity, gender identity, sexual orientation, age, class, or geographic location.
- > Lead awareness raising and advocacy efforts with service providers, families, policymakers, and community actors to challenge exclusion and harmful stereotypes, building a shared understanding of legal capacity and supported decision-making and promoting rights-based approaches to SRHR and decision-making grounded in the leadership and experiences of women and gender-diverse persons with disabilities.
- > Engage families as supportive partners in advancing the right to legal capacity in the SRHR context by developing a shared understanding and dialogue grounded in trust, respect, and autonomy of women and gender and gender-diverse persons with disabilities.
- > Create or support peer-led groups, networks, and safe spaces in which women and gender-diverse persons with disabilities can exchange experiences, build solidarity, and access community-based support for SRHR decision-making.
- > Document and amplify best practice examples, strategies, and models of rights-based supported decision-making (especially non-coercive, culturally rooted models) of SRHR support.

To organizations of persons with disabilities (Cont.):

- > Establish or collaborate on community-based monitoring systems to document violations of SRHR and denials of legal capacity, advocating for redress with relevant authorities or human rights mechanisms.
- > Develop internal accountability processes to assess and improve organizational practices related to gender inclusion and justice.



To both sexual and reproductive rights organizations and organizations of persons with disabilities:

- > Strengthen cross-movement collaboration to define a common advocacy strategy to guarantee the effective implementation of the right to legal capacity in sexual and reproductive decision-making.
- > Adopt a disability and gender intersectional perspective within your work. Ensure women and gender-diverse persons with intellectual disabilities and women and gender-diverse persons with psychosocial disabilities and their priorities are part of the decision-making and leadership of your organization's work.
- > Jointly develop and provide guidance and resources to train key stakeholders on the implementation of the right to legal capacity in the SRHR context. Ensure the process is led by women and gender-diverse persons with disabilities and that the content of the training is grounded in an intersectional perspective.
- > Ensure all your advocacy efforts apply an intersectional lens, addressing the unique and disproportionate barriers faced by women and gender-diverse persons with disabilities due to other identities, such as race and ethnicity, gender identity, sexual orientation, age, class, or geographic location.
- > Collaborate on shared resource mobilization and joint funding proposals to strengthen sustainable, disability-led SRHR initiatives that center legal capacity, bodily autonomy, and intersectionality.

Promising Practices

This report has outlined the many ways in which women with intellectual disabilities and women with psychosocial disabilities are denied their right to legal capacity in the SRHR context.

It doesn't have to be this way.

Supported decision-making is one well-known alternative to guardianship and other forms of substitute decision-making. Where substitute decision-making involves others making decisions for persons with disabilities, supported decision-making allows many persons with disabilities to make their own decisions with the support of a circle of people they know, trust, and—importantly—have chosen for themselves.

Though we might not recognize it, most of us use supported decision-making whenever we make impactful decisions. Supported decision-making means talking through difficult choices with people we trust. Those people help us weigh the benefits and drawbacks of a decision. They might explain topics to us that we don't understand. We then take all that information and feedback to make our own decisions. Supported decision-making is based on the idea that persons with disabilities have the right to be given the same opportunity.

Supported decision-making is a flexible tool that can be changed to best fit what a person wants and needs, so the exact format varies. In all its forms, supported decision-making empowers the person with a disability—not their supporters—to make the final decision. Therefore, it is a tool that is particularly valuable for women and gender-diverse persons with disabilities making sexual and reproductive health decisions.

It is important to remember that the right to legal capacity of women and gender-diverse persons with disabilities does not depend on them choosing to use supported decision-making tools. Everyone has the right to make decisions and to refuse support if they do not want it. It is essential, however, that supported decision-making tools are offered to anyone who would like to benefit from using them. Having these and similar supports available is an important step forward in the implementation of the right to legal capacity.

The supported decision-making model has been widely written and talked about. The work of activists, organizations, and governments who have championed supported decision-making and other alternatives to substitute decision-making for years is a great resource to learn more about supported decision-making. British Columbia (Canada) was the first jurisdiction to pass a law allowing people to receive support in their decision-making while still preserving their legal capacity.¹²² Peru and Colombia have also been leaders in the supported decision-making movement. After years of sustained organizing and advocacy efforts, these countries abolished their guardianship regimes in favor of supported decision-making (in 2018 and 2019, respectively).

The successful implementation of supported decision-making and other alternatives to substitute decision-making laws requires intentionality, collaboration, and dedication. Below are a few promising examples of how different regions are approaching alternatives to substitute decision-making, which could be replicated worldwide.





Africa: Ensuring minimum federal protections and including a gender lens

The long-awaited Kenyan Persons with Disabilities Bill was signed into law in May 2025. While the effects of this law remain to be seen, its structure responds to two important demands of the disability and gender rights movements. First, it guarantees the right to legal capacity for all persons with disabilities in Kenya by imposing obligations upon both the national and county-level governments—an essential step for countries with federal or quasi-federal forms of government.¹²³ Second, in addition to providing for a general right to legal capacity, which applies to all persons with disabilities, it has a separate provision that specifically addresses women with disabilities.¹²⁴ This provision mandates, among other things, that women with disabilities have the right to maintain and control their own fertility.



Africa: 24/7 Support Line

Policymakers and funders should learn from and resource existing disability-led initiatives, like **[She Writes Woman](#)**. She Writes Woman is a Nigerian woman- and disability-led organization that runs a 24/7 toll-free helpline. The helpline, in addition to providing psychosocial support and mental health first response, provides women with psychosocial disabilities in Nigeria with the information they need to make their own decisions and give informed consent in healthcare and other settings. The helpline is staffed by trained counselors, including women with psychosocial disabilities themselves.



Asia: Funding community inclusion models

Governments would do well to partner with and fund community inclusion models, such as the Circle of Care model developed by the [Seher Community Mental Health and Inclusion Program](#) in India. The Circle of Care model supports persons with intellectual or psychosocial disabilities in making their own decisions—free of coercion—by first identifying people they trust, services they use, and community groups (e.g., support, recreational, or spiritual groups) they belong to and can rely on for support in making decisions and in moments of need or crisis. Then, the person with a disability develops a support plan using an Eight-Point Framework, which outlines eight domains for which a person may want support, as well as types of support a person can choose (or not) to pursue in each domain. Personal autonomy in decision-making and community care are central to Seher’s model.



Europe: The Open Dialogue Model

Many clinical practitioners in Finland (and beyond) have changed their policies and practices to better support and empower persons with psychosocial disabilities to make their own decisions about their care.¹²⁵ In the Open Dialogue Model, the person with a psychosocial disability and a trusted circle of people they choose to support them meet regularly with a healthcare provider(s). In these gatherings, the group talks through the positives and negatives of different options, after which the person with the psychosocial disability makes the final decision. While originally developed in response to legal capacity violations in the psychiatric context, the model seems readily transferable to other specialties, including sexual and reproductive health.



North America: *Incorporating stakeholder capacity strengthening into supported decision-making legislation*

Appreciating that the full realization of the right to legal capacity is dependent upon the ability and willingness of stakeholders to respect it, the supported decision-making law in the state of Virginia (United States) goes beyond the important first step of recognizing supported decision-making as an alternative to guardianship.¹²⁶ It also requires that a state government entity (there, the Department of Behavioral Health and Developmental Services) create and run a program dedicated to educating and training key stakeholders—such as families and medical, legal, and financial professionals—on the availability of supported decision-making and how to meaningfully implement it.¹²⁷



The Pacific: *Supporting patients' decision-making: A clinical tool for sexual and reproductive healthcare providers*

Understanding that so many legal capacity violations occur in healthcare settings, a tool developed by Family Planning Australia aims to provide healthcare providers with the training and tools they need to support patients with intellectual disabilities in making their own decisions about key topics in sexual and reproductive health. These topics include many of the decisions that women in this report described being prevented from making, including whether to have sexual intercourse, what type of contraception to use, and whether to become a mother. The tool can be downloaded for free [here](#).



The Pacific: *Establishing culturally safe tools and practices*

When investing in alternatives to substitute decision-making, it is essential that governments and others do not force a one-size-fits-all model upon diverse communities. From 2022-2024, the Australian government piloted a project to develop culturally safe supported decision-making tools and training materials in collaboration with First Nations peoples. You can learn more about the project [here](#).



South America: *Supporting families in respecting the sexuality and related decision-making of their children and adolescent family members with disabilities*

Asdown Colombia, together with Profamilia, Liga Colombiana de Autismo, and the Fondo de Población de las Naciones Unidas (UNFPA) Colombia, created and published a detailed support guide for families called *Discovering Sexuality as a Family: Tools and supports to address comprehensive sexuality education for children and adolescents with disabilities*. This tool debunks harmful stereotypes that underpin so many legal capacity violations in the SRHR context and provides guidance to families on how to talk with their young family members with different types of disabilities (including intellectual disabilities and psychosocial disabilities) about sexuality and how to support their decision-making in these areas. You can download the tool (in Spanish) for free [here](#).

Additional Definitions

The definitions that are not integrated throughout the report are included in the list below.



Do you want to go back to reading the report?

Click on each term to go back to the first time it appears in the text.

Best interests

The best interest standard is a legal principle originally found in the Convention on the Rights of the Child, but that many substitute decision-making laws mistakenly apply to adults with disabilities. According to this principle, guardians (and others, depending on the context) are empowered to make decisions that they believe are best for a person, replacing that person's decision-making.

The Committee on the Rights of Persons with Disabilities makes clear that this legal principle cannot be applied to adults or justified on the basis of disability.

Gender-diverse persons

As explained by the United Nations Independent Expert on sexual orientation and gender identity, gender-diverse persons is used as an umbrella term "to refer to persons to whose gender identity, including their gender expression, is at odds with what is perceived as the gender norm in a particular context at a particular point in time, including those who do not place themselves in the male/female binary".¹²⁸

High support needs

Persons who are perceived to have high support needs are persons with numerous types of accessibility needs. These accessibility needs may include support with things like understanding and processing information, communicating, going to the bathroom, or eating.

Additional Definitions

Persons with intellectual disabilities

Persons with intellectual disabilities are individuals who experience discrimination and barriers to inclusion based on actual or perceived cognitive functioning and skills. Persons with intellectual disabilities face barriers that make it more difficult for them to take part equally in their communities, but with support and through more accessible systems they can be fully included in all parts of their lives.

Just like someone may need interpretation support to participate in a conversation held in a language they do not speak, persons with intellectual disabilities may require support to be able to do certain things. They may need support communicating, learning new information, understanding abstract ideas, or doing daily tasks (e.g., self-care, transportation).

Everyone is different. Not everyone with intellectual disabilities needs support in these ways, and some persons with intellectual disabilities may need support in different ways.

Persons with psychosocial disabilities

Persons with psychosocial disabilities include those with a mental health condition that, in interaction with various societal barriers, may hinder their full and effective participation in society on an equal basis with others.

The definition of 'Persons with psychosocial disabilities' has been derived from the CRPD description of disability and is inclusive of persons who identify as "users and survivors of psychiatry," "mad" persons, or persons with intersectional and neurodiverse identities. This language is preferred to "mental illness," which evokes legal and societal barriers to participation.

Psychosocial disability also refers to a person's experience of discrimination, which may include segregation, confinement, violations of autonomy and physical and mental integrity, and/or denial of desired supports and accommodations, based on their subjective distress or disturbance or others' attribution to them of distress or disturbance.

Self-advocate

Self-advocates are persons with intellectual disabilities who have received human rights training and who speak up for themselves and their communities about the things that are important to them.

Additional Definitions

Substitute decision-making

Substitute decision-making is the process by which one person makes decisions for, or on behalf of, another person.

While substitute decision-making takes many forms, it always involves an individual being denied the right to make a decision, that right being given to another person or entity, and that person or entity making decisions for the individual based on what they think is best. See *Best interests* above.

Guardianship is the most common example of a law that allows for substitute decision-making.

Supported decision-making

Supported decision-making is one well-known alternative to guardianship and other forms of substitute decision-making. Where substitute decision-making involves others making decisions for persons with disabilities, supported decision-making allows persons with disabilities to make their own decisions with the support of people they know, trust, and—importantly—have chosen for themselves.

Supported decision-making is a flexible tool that can be changed to best fit what a person wants and needs, so the exact format varies. In all its forms, supported decision-making empowers the person with a disability—not their supporters—to make the final decision.

Will and preferences

Will and preferences is a legal and ethical principle. This principle requires that, when supporting a person with a disability in decision-making, others respect that person's wishes.

Respecting a person's will and preferences stands in contrast to the best interests standard and is in line with the human rights standard of supported decision-making.

Endnotes

¹ Comm. on the Rts. of Pers. with Disabilities, *General Comment No. 1: Article 12 Equal Recognition Before the Law*, ¶8, U.N. Doc. CRPD/C/GC/1 (2014) [hereinafter, CRPD Comm.]. <https://docs.un.org/CRPD/C/GC/1>

² U.N. Women Reg'l Off. for Asia and the Pacific, *Closing the Justice Gap for Women with Intellectual and/or Psychosocial Disabilities in Asia and the Pacific*, at 7, (2023), https://asiapacific.unwomen.org/sites/default/files/2023-12/ap-c453-00-fa_final_kp3-report.pdf

³ CRPD Comm., *supra* note 1, at ¶¶8,13.

⁴ *Id.* at ¶ 13.

⁵ *Id.* at ¶14.

⁶ *Id.* at ¶4.

⁷ *Id.* at ¶ 29 (b).

⁸ *Id.* at ¶ 29 (e).

⁹ *Id.* at ¶ 29 (a),(f)

¹⁰ *Id.* at ¶ 29 (g).

¹¹ *Id.* at ¶ 29 (c).

¹² For example, legislation in Albania. See *Kodi i Familjes* [Family Code], Ligj nr. 9062, Fletorja Zyrtare e Republikës së Shqipërisë (2003) (Alb.), translated in Chemonics International Inc., *Family Code of Albania*, Law Number 9062, (2004), <https://faolex.fao.org/docs/pdf/alb208226.pdf> (Unofficial English translation, last visited Aug. 1, 2025).

¹³ CRPD Comm., *supra* note 1.

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.* at ¶13.

¹⁷ *Id.* at ¶ 28.

¹⁸ *Id.* at ¶ 9.

¹⁹ *Id.* at ¶3.

²⁰ U.N. Hum. Rts. Council 37th Sess., *Report of the Special Rapporteur on the Rights of Persons with Disabilities – Thematic Study on the Right of Persons with Disabilities to Equal Recognition Before the Law*, ¶13, U.N. Doc. A/HRC/37/56 (Dec. 12, 2017), <https://docs.un.org/A/HRC/37/56>.

²¹ Such as the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Convention on the Elimination of All Forms of Racial Discrimination.

²² This type of law is thought to have its origins in the ancient Greek and Roman Empires (1) and was subsequently imposed—along with accompanying legal systems—upon many others through settler-colonial and colonial violence by predominantly white nations in the Global North (2). Many countries have maintained these laws after gaining independence (3). (1) See, e.g., Robert Dinerstein, *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 *Ilsa J. INT'L & COMPAR. L.* 436, 436 (2016), https://digitalcommons.wcl.american.edu/facsch_lawrev/1314. (2) See, e.g., Yun chien Chang et al., *Colonial Experiences and Contemporary Laws*, 2 *J. L. & EMPIRICAL ANALYSIS* 203, 203-31 (2025), <https://doi.org/10.1177/2755323X241308009>; Salmon A. Shomade, *Colonial Legacies Endure in Africa's Legal Systems — Undermining Rule of Law*, WASH. POST (Mar. 18, 2022), <https://www.washingtonpost.com/outlook/2022/03/18/colonial-legacies-endure-africas-legal-systems-undermining-rule-law/> (3) See, e.g., Hisyam Ikhtiar Mulia et al., *Assessment of the Guardianship System for Persons with Psychosocial Disability in Indonesia*, 26 *SCANDINAVIAN J. DISABILITY RSCH.* 301, 301-02 (2024).

²³ See *Britney Spears: Singer's conservatorship explained*, BBC (Nov. 12, 2021), <https://www.bbc.com/news/world-us-canada-53494405>.

²⁴ See, e.g., Bhargavi V. Davar, *Identity Constructions for 'Mentally Disturbed' Women: Identities Versus Institutions*, in *GENDERING MENTAL HEALTH: KNOWLEDGES, IDENTITIES AND INSTITUTIONS* 193, 211 Bhargavi V. Davar & T.K. Sundari Ravindran (eds., 2015); Linda Steele & Beth Goldblatt, *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, 81 (Chris Bobel et al. eds., 2020); *THE RAINBOW SUPPORT GRP. GUIDEBOOK FOR LGBTQ+ & INTELL. AND DEVELOPMENTAL DISABILITIES* (2023), <https://rainbowguidebook.com/chapters/6-life-experiences/#denied-self-determination>.

²⁵ For example, CRPD Comm., *Concluding observations on the combined initial and second periodic reports of Malawi*, ¶25, U.N. Doc. CRPD/C/MWI/CO/1-2 (Oct. 5, 2023); *Concluding observations on the initial report of India*, ¶26, U.N. Doc. CRPD/C/IND/CO/1 (Oct. 29, 2019).

²⁶ CRPD Comm., *Guidelines on Deinstitutionalization, Including in Emergencies*, ¶6, U.N. Doc. CRPD/C/5 (Oct. 10, 2022), <https://docs.un.org/CRPD/C/5>.

²⁷ U.N. Hum. Rts. Council, *supra* note 20, at ¶13.

²⁸ See, e.g., Anna Arstein-Kerslake, LEGAL CAPACITY & GENDER: REALISING THE HUMAN RIGHT TO LEGAL PERSONHOOD AND AGENCY OF WOMEN, DISABLED WOMEN, AND GENDER MINORITIES 126-27 (2021); and Ma'ayan Anafi, *It's Time to Embrace Disabled Trans People*, NAT'L WOMEN'S L. CTR. (Mar. 31, 2023), <https://nwlc.org/its-time-to-embrace-disabled-trans-people/>.

²⁹ U.N. General Assembly Official Records 72nd Sess., *Report of the Special Rapporteur on the Rights of Persons with Disabilities on Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, ¶11, U.N. Doc. A/72/133 (July 14, 2017) [hereinafter U.N.GAOR], <https://docs.un.org/A/72/133>.

³⁰ *Id.* at ¶10; Women Enabled Int'l & U.N. Population Fund, *Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights*, at 95, (2018) [hereinafter WEI & UNFPA]. <https://womenenabled.org/wp-content/uploads/2021/02/WEI-and-UNFPA-Guidelines-Disability-GBV-SRHR-English.pdf>.

³¹ Special Envoy on Disability and Accessibility, *Modelo de protocolo de maternidad para mujeres con discapacidad* at 9 (2023), <https://www.senadis.gob.cl/descarga/i/7439/documento>.

³² U.N. GAOR, *supra* note 29.

³³ UNFPA, *Bodily Autonomy: A Cornerstone for Achieving Gender Equality and Universal Access to Sexual and Reproductive Health and Rights*, at 1, (Apr. 1, 2021), <https://www.unfpa.org/publications/bodily-autonomy-cornerstone-achieving-gender-equality-and-universal-access>,

³⁴ *Id.*

³⁵ WEI & UNFPA, *supra* note 30, at 16.

³⁶ Int'l Disability Caucus, *Working Group on Health Article 21 – Informed Consent*, <https://www.un.org/esa/socdev/enable/rights/documents/ahc6idcda21infosheet.doc> (last modified Aug. 4, 2005).

³⁷ Int'l Fed'n of Gynecology & Obstetrics, *Ethics and Professionalism Guidelines for Obstetrics and Gynecology*, at 20 (Frank A. Chervenak & Laurence B. McCullough eds., 2021), <https://www.figo.org/sites/default/files/2021-11/FIGO-Ethics-Guidelines-onlinePDF.pdf>.

³⁸ WEI & UNFPA, *supra* note 30, at 18.

³⁹ Int'l Fed'n of Gynecology & Obstetrics, *supra* note 37, at 21.

⁴⁰ CRPD Comm., *supra* note 1, at ¶41.

⁴¹ WEI & UNFPA, *supra* note 30, at 17.

⁴² U.N. Hum. Rts. Comm. 43rd Sess., *Report of the Office of the United Nations High Commissioner for Human Rights - Thematic Study on Awareness-Raising Under Article 8 of the Convention on the Rights of Persons with Disabilities*, ¶15, U.N. Doc. A/HRC/43/27 (Dec. 17, 2019), <https://docs.un.org/A/HRC/43/27>.

⁴³ U.N. Hum. Rts. Comm. 43rd Sess., *Report of the Special Rapporteur on the Rights of Persons with Disabilities - Thematic Study on the Impact of Ableism in Medical and Scientific Practice, Research and Experimentation*, ¶9, U.N. Doc. A/HRC/43/41 (Dec. 17, 2019), <https://docs.un.org/A/HRC/43/41>.

⁴⁴ *Id.*

⁴⁵ To learn more about the connections between patriarchy and legal capacity violations, see, e.g., Shubhangi Vaidya, *Women with Disability and Reproductive Rights: Deconstructing Discourses*, 45 SOC. CHANGE 517, 517-33 (2015), <https://doi.org/10.1177/0049085715602787>; Bhargavi V. Davar, *supra* note 24, at 199-204; Malavika Parthasarathy, *Integrating Mental Health Perspectives into the Legal Discourse on Reproductive Justice in India*, 6 J. NAT. L. U. DELHI 21, 21-38 (2019), <https://doi.org/10.1177/2277401719870643>. For the connections between colonialism and legal capacity violations, see, e.g., Bhargavi V. Davar, *Delivering Justice, Withdrawing Care: The Norms and Etiquettes of 'Having' a Mental Illness*, in GENDERING MENTAL HEALTH: KNOWLEDGES, IDENTITIES, AND INSTITUTIONS 1, 3-4, 21 (Bhargavi V. Davar & T.K. Sundari Ravindran eds., 2015); Bhargavi V. Davar, *supra* note 24, at 213; Bhargavi V. Davar, *Legal Capacity and Civil and Political Rights for People with Psychosocial Disabilities*, in DISABILITY, GENDER, AND THE TRAJECTORIES OF POWER (Asha Hans ed., 2d ed. 2025); Bhargavi V. Davar, *Globalizing Psychiatry and the Case of 'Vanishing' Alternatives in a Neo-Colonial State*, 1 DISABILITY & GLOB. S. 266, 267-71 (2014); and Ruby Dhand, *Indigenous Peoples with Disabilities*

and Canadian Mental Capacity Law, in ENDERING CAPACITY, PARTICIPATION, AND VALUES IN COMPARATIVE LEGAL PERSPECTIVE 100 (Camilla Kong et al. eds., 2023). For the connections between racism and white supremacy and legal capacity violations, see, e.g., Yolanda Suarez-Balcazar et al., *Reproductive Justice for Black, Indigenous, Women of Color: Uprooting Race and Colonialism*, 73 AM. J. CMTY. PSYCH. 159, 161-62 (2024), <https://doi.org/10.1002/ajcp.12650>; Tina Minkowitz, *Legal Capacity from a Psychosocial Disability Perspective: A Discussion Paper*, CTR. FOR HUM. RTS. OF USERS AND SURVIVORS OF PSYCH., ¶¶1, 3 (2014); Anna H. Chodos and Sarah Hooper, *Context, Humility, and Caution in Guardianship Determination*, 70 J. AM. GERIATRICS SOC'Y 3058, 3058-60, (2022), <https://doi.org/10.1111/jgs.18067>; Alexandra Minna Stern, *Forced Sterilization Policies in the US Targeted Minorities and those with Disabilities – and Lasted into the 21st Century*, THE CONVERSATION, (Aug. 26, 2020), <https://theconversation.com/forced-sterilization-policies-in-the-us-targeted-minorities-and-those-with-disabilities-and-lived-into-the-21st-century-143144>; Alexandra Minna Stern, *Sterilized in the Name of Public Health: Race, Immigration, and Reproductive Control in Modern California*, 95 AM. J. PUB. HEALTH 1128, 1128-38, (2005), <https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2004.041608>; *Coercive and Cruel: Sterilisation and its Consequences for Romani Women in the Czech Republic (1966-2016)*, EUROPEAN ROMA RTS. CTR. (Nov. 2016), https://www.errc.org/uploads/upload_en/file/coercive-and-cruel-28-november-2016.pdf; *China Cuts Uighur Births with IUDs, Abortion, Sterilization*, THE ASSOCIATED PRESS (June 28, 2020), <https://apnews.com/article/ap-top-news-international-news-weekend-reads-china-health-269b3de1af34e17c1941a514f78d764c>. For the connections between ageism and legal capacity violations, see, e.g., U.N. GAOR 74th Sess., *Report of the Special Rapporteur on the Rights of Persons with Disabilities on the Rights of Older Persons with Disabilities*, ¶8, U.N. Doc. A/74/186 (July 17, 2019), <https://docs.un.org/A/74/186>; and Tina Minkowitz, *Legal Capacity from a Psychosocial Disability Perspective: A Discussion Paper*, CTR. FOR HUM. RTS. OF USERS AND SURVIVORS OF PSYCH., ¶¶1, 3 (2014). And for the connections between poverty and legal capacity violations, see, e.g., Anna H. Chodos & Sarah Hooper, *Context, Humility, and Caution in Guardianship Determination*, 70 J. AM. GERIATRICS SOC'Y 3058, 3058-60 (2022), <https://doi.org/10.1111/jgs.18067>.

⁴⁶ See, e.g., Renu Addlakha, Janet Price, & Shirin Heidari, *Disability and Sexuality: Claiming Sexual and Reproductive Rights*, 25 REPROD. HEALTH MATTERS 4, 4-9 (2017), <https://doi.org/10.1080/09688080.2017.1336375>; Malavika Parthasarathy, *supra* note 45, at 21, 24, 33; Shubhangi Vaidya, *supra* note 45, at 521-22; and *Investigación sobre la Situación*

de las Mujeres con Discapacidad Intelectual y del Desarrollo en Relación con sus Derechos Sexuales y Reproductivos, PLENA INCLUSIÓN ESPAÑA, (2022), <https://www.plenainclusion.org/wp-content/uploads/2023/03/Informe-final-Investigacion-situacion-de-las-mujeres-con-discapacidad-intelectual-y-del-desarrollo-derechos-sexuales-y-repr.pdf>.

⁴⁷ See, e.g., Transforming Cmtys. for Inclusion [hereinafter, TCI], *Written Submission to the Committee on the Elimination of Discrimination against Women*, at 5-6, (2022), <https://www.ohchr.org/sites/default/files/documents/hrbodies/cedaw/general-discussion/2023/gr40-tci.docx>.

⁴⁸ Inclusion Int'l, *Independent but Not Alone: Global Report on the Right to Decide*, at 79-81, (June 2014), https://s38312.pcdn.co/wp-content/uploads/Independent-But-Not-Along_-final.pdf. For examples of what families have said they need to support their family members with decision-making, see *id.* at 82-84.

⁴⁹ CRPD Comm., CEDAW Comm., & UN Women, *Joint Statement: Ending Sexual Harassment Against Women and Girls with Disabilities*, (Oct. 22, 2020), https://www.ohchr.org/sites/default/files/Documents/HRBodies/CEDAW/Statements/JointStatement_UNW_CEDAW_CRPD.docx.

⁵⁰ CRPD Comm., *supra* note 1, at ¶42.

⁵¹ Convention on the Rights of Persons with Disabilities, art. 25(d), *opened for signature* Mar. 30, 2007, 2515 U.N.T.S. 3.

⁵² U.N. GAOR, *supra* note 29, at ¶40.

⁵³ U.N. Hum. Rts. Council, *supra* note 20, at ¶28.

⁵⁴ Theresia Degener, *Disability in a Human Rights Context*, LAWS, at Section 2, (Aug. 2016), <https://doi.org/10.3390/laws5030035>.

⁵⁵ To understand the other models of disability, see *id.*

⁵⁶ UNFPA, *Toolkit for Advancing Human Rights-Based Universal Sexual and Reproductive Health at 21*(2022), https://www.unfpa.org/modules/custom/unfpa_global_uhc/assets/pdfs/SRHR-Full-Toolkit-final-240513.pdf. For an example of self-advocates talking about the importance of SRHR information, see *Mi sexualidad, mi derecho, Por qué hablar de Educación Sexual?* <https://misexualidadmiderecho.com/educacion-sexual/> (last visited Aug. 5, 2025).

⁵⁷ See Human. and Inclusion, Access to Sexual and Reproductive Health and Rights Information and Services Perspectives of women and girls with disabilities in Uganda and Bangladesh, at 26-29, (Aug. 2021), https://www.hi-us.org/sn_uploads/document/1257_HI_report_research_2022_P6_17_10_22_DIGITAL.pdf.

⁵⁸ Inclusion Int'l, *supra* note 48.

⁵⁹ *Id.*

⁶⁰ In particular, articles 12, 14, 16, 17, 23, and 25.

⁶¹ World Health Organization (WHO), *Eliminating forced, coercive and otherwise involuntary sterilisation. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO* at 5 (May 3, 2014), <https://www.who.int/publications/i/item/9789241507325>.

⁶² *Id.* at 1.

⁶³ U.N. Hum. Rts. Council 31st Sess., *Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment - Gender Perspectives on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment*, ¶¶5, U.N. Doc. A/HRC/31/57 (Jan. 5, 2016), <https://docs.un.org/A/HRC/31/57>; U.N. Hum. Rts. Council 22nd Sess., *Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, Juan E. Méndez - *Thematic Report on Torture and Ill-Treatment in Health-Care Settings*, ¶¶48, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013), <https://docs.un.org/A/HRC/22/53>.

⁶⁴ Open Soc'y Foundns., *Against Her Will: Forced and Coerced Sterilization of Women Worldwide*, at 2, (2011), <https://www.opensocietyfoundations.org/publications/against-her-will-forced-and-coerced-sterilization-women-worldwide>.

⁶⁵ *Fact Sheet: Eugenics and Scientific Racism*, NIH NAT'L HUM. GENOME RSCH. INST., <https://www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism> (last updated May 18, 2022).

⁶⁶ U.N. GAOR, *supra* note 29.

⁶⁷ See, e.g., Malavika Parthasarathy, *supra* note 45, at 21, 24.

⁶⁸ For instance, Singapore. See CRPD Comm., *Concluding Observations on the initial report of Singapore*, ¶¶35, U.N. Doc. CRPD/C/SGP/CO/1 (Oct. 5, 2022).

⁶⁹ CRPD Comm., *supra* note 1.

⁷⁰ Committee on the Rights of the Child, *General Comment No. 14 On the Right of the Child to have his or her Best Interests Taken as a Primary Consideration*, ¶¶4, U.N. Doc. CRC/C/GC/14 (May 29, 2013), <https://docs.un.org/CRC/C/GC/14>.

⁷¹ UNFPA, *Young Persons with Disabilities: Global Study on Ending Gender-Based Violence, and Realising Sexual and Reproductive Health and Rights*, at 21, (2018), <https://www.unfpa.org/featured-publication/young-persons-disabilities-global-study-ending-gender-based-violence-and>; and Anna Arstein-Kerslake, *supra* note 28, at 125-26.

⁷² U.N. Hum. Rts. Council 22nd Sess., *supra* note 63, at ¶¶65, 66. See also Hum. Rts. Comm., *General Comment No. 28: Article 3 The Equality of Rights Between Men and Women*, ¶¶7, 20, U.N. Doc. CCPR/C/21/Rev/1/Add.10 (Mar. 29, 2000); and UNFPA, *supra* note 33.

⁷³ UN Women, *A Closer Look at Sexual and Reproductive Health and Rights of Women and Girls: Three Decades of the Beijing Platform for Action*, at 5, (2024), <https://www.unwomen.org/en/digital-library/publications/2024/03/a-closer-look-at-sexual-and-reproductive-health-and-rights-of-women-and-girls>.

⁷⁴ *Id.*

⁷⁵ Validity Found., *Ending Violence, Ensuring Inclusion: Strengthening Protections Against Gender- and Disability-Based Violence*, at 29-30, (2025), <https://validity.ngo/wp-content/uploads/2025/05/D2.3-International-Synthesis-Report-1.pdf>.

⁷⁶ CRPD Comm., *supra* note 1, at ¶¶13, 29(f).

⁷⁷ For instance, many state laws in the United States. See, e.g., Robyn M. Powell, *Legal Ableism: A Systemic Review of State Termination of Parental Rights Laws*, 101 WASH. U. L. REV. 423, 455-65 (2022), <https://dx.doi.org/10.2139/ssrn.437840>.

⁷⁸ CRPD Comm., *General Comment No. 3: Article 6 Women and Girls with Disabilities*, ¶¶46, U.N. Doc. CRPD/C/GC/3 (Nov. 25, 2016), <https://docs.un.org/CRPD/C/GC/3>.

⁷⁹ *A Third of UN Member States Don't Permit People with Mental Illness the Right to Vote or Marry*, TAYLOR & FRANCIS NEWSROOM, Oct. 10, 2016, <https://newsroom.taylorandfrancisgroup.com/a-third-of-un-member-states-dont-permit-people-with-mental-illness-the-right-to-vote-or-marry>.

⁸⁰ CRPD Comm., *supra* note 78.

⁸¹ For example, in France, according to the law, the marriage of persons with disabilities under guardianship or with restricted legal capacity can be subject to objection by guardians and third parties, as criticized by the CRPD Committee. See CRPD Comm., *Concluding Observations on the initial report of France*, ¶48, U.N. Doc. CRPD/C/FRA/CO/1 (2021).

⁸² For example, legislation in Albania, Family Code Law No. 9062, *supra* note 12.

⁸³ CRPD Comm., *supra* note 1, at ¶8.

⁸⁴ *Id.*

⁸⁵ Gabriella Garbero, *Rights Not Fundamental: Disability and the Right to Marry*, 14 NAT'L ST. LOUIS U. J. HEALTH L. & POL'Y 587, 587-89 (2021), <https://scholarship.law.slu.edu/cgi/viewcontent.cgi?article=1272&context=jhlp>.

⁸⁶ Andrew Pulrang, *What's Next in 'Marriage Equality' For People with Disabilities?*, FORBES, Mar. 31, 2022, <https://www.forbes.com/sites/andrewpulrang/2022/03/31/whats-next-in-marriage-equality-for-people-with-disabilities/?sh=6a79c22b6eb7>.

⁸⁷ Human. and Inclusion, *supra* note 57, at 31.

⁸⁸ Tatiana Perilla & Teresa Larsen, *Self-Determination & Dignity of Risk Factsheet*, MENTAL HEALTH & DEVELOPMENTAL DISABILITIES TRAINING CTR., <https://www.mhddcenter.org/wp-content/uploads/2020/07/Self-Determination-Dignity-of-Risk-Fact-Sheet.pdf> (last visited Aug. 5, 2025).

⁸⁹ NSW Ageing & Disability Comm'n, *Capacity Toolkit: Dignity of Risk*, NSW GOV'T: CMTYS. & JUSTICE, <https://ageingdisabilitycommission.nsw.gov.au/content/dcj/dcj-website/dcj/resources/capacity-toolkit/decision-making-and-capacity-module/chapter-4-risk-is-part-of-decision-making/dignity-of-risk.html> (last updated Nov. 27, 2024).

⁹⁰ Valerie Bradley, Dorothy Hiersteiner, & Mary Lou Bourne, *What Do NCI Data Reveal About the Guardianship Status of People with IDD? National Core Indicators Data Brief*, at 5, (Apr. 2019), https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf.

⁹¹ Other defining elements of an institution are 1) obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; 2) isolation and segregation from independent life in the community; 3) identical activities in the same place for a group of individuals

under a certain authority; 4) supervision of living arrangements; and 5) a disproportionate number of persons with disabilities in the same environment. See CRPD Comm., *supra* note 26, at ¶15.

⁹² *Id.*

⁹³ CRPD Comm., *General Comment No. 5 On Living Independently and Being Included in the Community*, ¶72, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), <https://docs.un.org/CRPD/C/GC/5>.

⁹⁴ U.N. Hum. Rts. Council 28th Sess., *Report of the Special Rapporteur on the Rights of Persons with Disabilities - Thematic Study on the Right of Persons with Disabilities to Live Independently and be Included in the Community*, ¶19, U.N. Doc. A/HRC/28/37 (Dec. 12, 2014), <https://docs.un.org/A/HRC/28/37>.

⁹⁵ Valerie Bradley et al., *supra* note 90.

⁹⁶ CRPD Committee, *supra* note 26, at ¶ 8.

⁹⁷ See, e.g., Malavika Parthasarathy, *supra* note 45, at 21, 23-24; Bhargavi V. Davar, *Delivering Justice, Withdrawing Care: The Norms and Etiquettes of 'Having' a Mental Illness*, in GENDERING MENTAL HEALTH: KNOWLEDGES, IDENTITIES, AND INSTITUTIONS 1, 3-4 (Bhargavi V. Davar & T.K. Sundari Ravindran eds., 2015); and Kate Moore, *Declared Insane for Speaking Up: The Dark American History of Silencing Women Through Psychiatry*, TIME, June 22, 2021, <https://time.com/6074783/psychiatry-history-women-mental-health/>.

⁹⁸ See, e.g., Malavika Parthasarathy, *supra* note 45; Davar, *supra* note 97; and Kate Moore, *supra* note 97.

⁹⁹ "Treated Worse Than Animals" Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India, HUM. RTS. WATCH, at 7, Dec. 3, 2014, <https://www.hrw.org/report/2014/12/03/treated-worse-animals/abuses-against-women-and-girls-psychosocial-or-intellectual>.

¹⁰⁰ TCI, *Reframing the Momentum from "Mental Health" to "Inclusion" of Persons with Psychosocial Disabilities: Report of the Classic Edition Plenary of TCI Asia Pacific*, at 37, (2020), <https://tci-global.org/wp-content/uploads/2022/03/Bali-Plenary-Report-2018.pdf>.

¹⁰¹ U.N. Hum. Rts. Council 44th Sess., *Report of the Independent Expert on Protection Against Violence and Discrimination Based on Sexual Orientation and Gender Identity, Practices of So-Called "Conversion Therapy"*, ¶17, U.N. Doc. A/HRC/44/53 (May 1, 2020), <https://docs.un.org/A/HRC/44/53>.

¹⁰² *Id.*, at ¶ 37.

¹⁰³ European Disability Forum, *European Human Rights Report 2024: Legal Capacity: Personal Choice and Control* at 82 (2024), <https://www.edf-feph.org/publications/human-rights-report-2024-legal-capacity/>.

¹⁰⁴ Natalie M. Chin, *Group Homes as Sex Police and the Role of the Olmstead Integration Mandate*, 42 NYU REV. L. & SOC. CHANGE 379 (2018), <https://ssrn.com/abstract=3249755>.

¹⁰⁵ Validity Found., *supra* note 75, at 36.

¹⁰⁶ See, e.g., Natalie M. Chin, *supra* note 104.

¹⁰⁷ *Ageism and Sexuality*, AGING EQUAL, <https://ageing-equal.org/ageism-and-sexuality/> (last visited Aug. 6, 2025).

¹⁰⁸ UNFPA, *My Body, My Life, My World – Operational Guide, Module 2, Gender-Based Violence*, at 9, (2022), https://www.unfpa.org/sites/default/files/resource-pdf/UNFPA-MBMLMW_MOD2-EN.pdf.

¹⁰⁹ WEI & UNFPA, *supra* note 30, at 49.

¹¹⁰ *Id.* at 50.

¹¹¹ WHO, *supra* note 61.

¹¹² U.N. Hum. Rts. Council 22nd Sess., *supra* note 63, at ¶¶7, 20, 65, 66.

¹¹³ CRPD Comm., *supra* note 78, at ¶46.

¹¹⁴ See, e.g. Mental Health Act (Fiji)(2010). The Mental Health Act permits involuntary commitment to mental health facilities, forced treatment based on a “mental disorder” diagnosis, and for forced surgeries, including non-emergency surgeries, if they are determined by a Review Board to be in the “best interest” of the patient. <https://www.laws.gov.fj/Acts/DisplayAct/542#>.

¹¹⁵ Children Act (2022) Pt. X § 127(2) (Kenya). The *Children Act* allows for an extension of (parental) guardianship beyond a child’s eighteenth birthday in certain circumstances, including disability. Other Kenyan laws permit substitute decision-making in specific contexts. For example, under the 2014 *Marriage Act*, people “suffering from any mental condition whether permanent or temporary” cannot give the consent needed to marry. *Marriage Act* (2014) Pt. I, § 11(2) (Kenya). Notably, promising disability legislation was just signed into law, which should force changes to current legal frameworks on the legal capacity of people with disabilities, including the *Children Act* and the *Marriage Act*. The Persons with Disabilities Act, No. 4 (2025) KENYA GAZETTE SUPPLEMENT No. 69. <https://new.kenyalaw.org/akn/ke/act/2025/4/eng@2025-05-27>.

¹¹⁶ *Ley Orgánica 2/2020, de 16 de diciembre, de modificación del Código Penal para la erradicación de la esterilización forzada o no consentida de personas con discapacidad incapacitadas judicialmente*, <https://www.boe.es/buscar/act.php?id=BOE-A-2020-16345>.

¹¹⁷ *Ley 8/2021, de 2 de junio, por la que se reforma la legislación civil y procesal para el apoyo a las personas con discapacidad en el ejercicio de su capacidad jurídica*, <https://www.boe.es/buscar/act.php?id=BOE-A-2021-9233>.

¹¹⁸ Mental Health Act, 2018, (Uganda). The *Mental Health Act* codifies the right to legal capacity for persons psychosocial disabilities while, at the same time, allowing for the appointment of guardian (personal representative) when the “court, on an application by a relative or a concerned person, determines that the person is not able to manage his or her affairs.” *Mental Health Act*, 2018, § 60(3)(b) (Uganda), <https://bills.parliament.ug/attachments/Mental%20Health%20Act%202018.pdf>.

¹¹⁹ OHIO REV. CODE § 2111, <https://codes.ohio.gov/ohio-revised-code/chapter-2111>.

¹²⁰ See Nat’l Res. Ctr. for Supported Decision-Making, Ohio, <https://supporteddecisionmaking.org/in-your-state/ohio/> (last updated Jan. 24, 2025). As of June 2025, there is a bill moving through the Ohio legislature that would—among other things—recognize supported decision-making as a less-restrictive alternative to guardianship, provide guidelines for supported decision-making plans, and direct the state department of developmental disabilities to develop model forms and informational materials about supported decision-making. S.B. 35, 136th Gen. Assemb. (Ohio 2025), <https://www.legislature.ohio.gov/legislation/136/sb35>. Critically, the bill makes clear that people have a right to both access and refuse this support: “An adult with a developmental disability who has entered into a supported decision-making plan is not precluded from acting independently of the plan, acting independently of one or more supporters identified in the plan, or seeking personal information without the assistance of a supporter. The adult’s choice to act independently of the plan or a supporter is not evidence of incapacity and shall not be used as such.” *Id.* at § 5123.681(E).

¹²¹ Suarez-Balcazar et al, *supra* note 45.

¹²² Representation Agreement Act, R.S.B.C. 405/1996 (Can.). https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96405_01.

¹²³ Persons with Disabilities Act, *supra* note 115, at Pt. 2, ¶4-5.

¹²⁴ *Id.* at ¶ 7, 10(e).

¹²⁵ Piers Gooding, *Compendium Report: Good Practices to Promote Voluntary Measures in Mental Health Services*, COUNCIL OF EUR. (Oct. 2021), <https://rm.coe.int/inf-2021-9-compendium-final-e/1680b11f60>.

¹²⁶ VA. CODE § 37.2-314.3 (2021), <https://law.lis.virginia.gov/vacode/title37.2/chapter3/section37.2-314.3/>.

¹²⁷ See Va. Dep't of Behav. Health and Developmental Servs. (DBHDS), *Supported Decision-Making 2025 Virtual Training Schedule*, <https://dbhds.virginia.gov/wp-content/uploads/2024/12/2025-Training-Schedule.pdf> (last visited Aug. 6, 2025).

¹²⁸ U.N. Hum. Rts. Off. of the High Comm'r, *The Struggle of Trans and Gender-Diverse Persons: Report of the Independent Expert on sexual orientation and gender identity*, <https://www.ohchr.org/en/special-procedures/ie-sexual-orientation-and-gender-identity/struggle-trans-and-gender-diverse-persons> (last visited Aug. 6, 2025).