

GUIDELINES

ETHICAL STANDARDS GUIDE



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UNDP AND UN WOMEN JOINT PROJECT
ON ADDRESSING STIGMA AND
DISCRIMINATION EXPERIENCED BY
WOMEN WITH DISABILITIES (ASDWD)



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ACRONYMS AND ABBREVIATIONS

ASDWD	Addressing Stigma and Discrimination experienced by Women with Disabilities
CRPD	Convention on the Rights of Persons with Disabilities
ETFG	Ethics Task and Finish Group
GBV	Gender-based violence
OPDs	Organizations of persons with disabilities
UNDP	United Nations Development Programme
UNEG	United Nations Evaluation Group
UNPRPD	United Nations Partnership on the Rights of Persons with Disabilities
WDSI	Women with Disabilities Stigma Inventory

EXECUTIVE SUMMARY

The Addressing Stigma and Discrimination Experienced by Women with Disabilities (ASDWD) project was led by the United Nations Development Programme (UNDP) and UN Women, with funding from the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) between October 2021 and June 2023. Implemented in four countries – Pakistan, Palestine, the Republic of Moldova and Samoa – the project aimed to address key challenges in overcoming stigma, discrimination and violence faced by women with disabilities.

This document outlines the guidance that was used throughout the project to minimize the risk of harm while engaging women with disabilities. The human-rights based approach and the ‘Do No Harm’ principle guided the conceptualization and implementation of these guidelines. While ethical and safety recommendations for research on violence against women exist, there is little guidance specifically on engaging and working with women with disabilities.

This guidance was developed through a working group that was chaired by research consultants and included representatives from all four pilot countries, who agreed on standards relating to ethical issues and data protection. The ethical guidance aimed to minimize the risk of harm at three levels: 1) the target population, including women and girls with disabilities and their family members and respective organizations of persons with disabilities (OPDs), civil society, policy and decision-makers and all others who provide data as part of their participation in this project; 2) those collecting data from the target population; 3) the organizations responsible for implementing this project.

The guidance draws on four key overarching concepts: informed consent; benefit, not harm; confidentiality; and data protection/transfer. The guidance also aligns with the UN Evaluation Group’s four ethical principles of integrity, accountability, respect and beneficence.¹

Finally, four key considerations are provided:

- **Accessibility:** in line with Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) affirming that all adults with disabilities have full legal capacity, and that people with disabilities should be provided with access to support to exercise capacity and decision-making.
- **Safety:** putting in place safeguarding measures to ensure the safety and privacy of participants and data collectors.
- **Signposting:** ensuring that the appropriate access to resources and organizations are available to women and girls with disabilities who may disclose safeguarding issues and/or need further support.
- **Making ethical decisions:** this draws on the six-step model outlined by the UN Ethics Office to provide support for action in difficult scenarios.

OVERVIEW OF ASDWD PROJECT

Globally, people with disabilities experience stigma and discrimination that limit the full exercise of their rights and impede sustainable development.² Women with disabilities experience intersectional stigma and discrimination based on their gender and disabilities, with COVID-19 further exacerbating these impacts.³ Prior to the ASDWD project, no CRPD-compliant tools existed to identify the drivers and impact of stigma towards women and girls with disabilities and consequently, there have been few evidence-based interventions to address stigma and discrimination in this population.

The UNPRPD-funded ASDWD project achieved its initial objective to address key challenges in overcoming stigma violence and discrimination towards women with disabilities. It co-developed a tool, the Women with Disability Stigma Inventory (WDSI) along with women with disabilities to gather evidence of disability-related stigma, discrimination and violence, and their impacts. The aim was to develop a tool that could be scaled up for advocacy and data-gathering at country level. In addition, behavioural insight approaches were used to design and pilot eight interventions undertaken by the four partner countries to reduce the stigma, violence and discrimination experienced by women with disabilities.

Article 4.3 of the CRPD legally anchors the obligation of States to “closely consult with and actively involve persons with disabilities...through their representative organizations”. Although the importance of this is increasingly gaining recognition, it is not always implemented and women with disabilities continue to be severely underrepresented in decision-making.⁴ A movement away from the “tokenistic” involvement of OPDs to inform research, evaluation and policy processes, and towards a meaningful participation and partnership with women with disabilities and their respective organizations, is key.⁵

The United Nations Disability Inclusion Strategy provides guidelines on consulting persons with disabilities,⁶ yet little specific guidance exists on consulting women and girls with disabilities, particularly where sensitive topics such as abuse and violence will be discussed or researched, to minimize the risks of harm for all involved. In the recent policy brief on responding and eliminating violence against women with disabilities, to address the invisibility and underrepresentation of women with disabilities in prevalence data, one of the recommendations was to establish ethical considerations and develop ethical guidelines for research.⁷

The ASDWD project ensured the meaningful participation of women with disabilities using the guidance presented to engage them at all stages of the conception of the WDSI. Women with disabilities across the four partner countries took on roles as consultants, OPD leads and data collectors. The findings of the WDSI are therefore evidence-informed, deliberative, participatory and action-oriented, and consequently can be built directly into policy dialogues. In addition, the work conducted under both the measurement and intervention arms of the project demonstrated that it is not only feasible but also vitally important and enriching to have women with disabilities involved in leading, decision-making, data collection and the dissemination of this work and its outcomes to those in power.

This ethical guidance presents key concepts and considerations for UN staff, consultants, researchers and others, and aligns with existing relevant strategies, guidelines and ethical principles to ensure that consultation and co-development of research, evaluation and policies involving women with disabilities are conducted in an ethical manner.

ASDWD ETHICAL STANDARDS GUIDE

AIMS

The ASDWD Project's aims, within the framework of the multi-country programmatic funding support from the UNPRDP Multi-Partner Trust Fund, are in line with the CRPD: to identify persons with disabilities and barriers that hinder their effective participation (Article 31[2]), and to produce the most effective interventions indicated. It also sought to increase the availability of high-quality, timely and reliable data disaggregated by disability⁸ and gender, among other criteria, in line with the 2030 Agenda for Sustainable Development.⁹ The ASDWD project and work undertaken to develop and test tools and interventions to address the project's aims observed certain standards relating to ethical issues and data protection.

A human-rights based approach, incorporating the [Do No Harm principle](#), guided the conceptualization and implementation of the ASDWD project to minimize the risk of harm. Doing no harm requires researchers, interviewers and others involved in the work to use methods and approaches to minimize the risk of harm at three levels:

- the target population, including women and girls with disabilities and their family members and respective OPDs, civil society, policy and decision-makers and all others who provide data as part of their participation in this project
- those collecting data from the target population
- the organizations responsible for the implementation of this UNPRPD-funded initiative jointly led by UNDP and UN Women.

Transparency of the coordination of the national rollout and accountability to all stakeholders (national and international) formed the basis of the Ethics Task and Finish Group (ETFG), which involved global, regional, and national partners from UNPRPD, UNDP and UN Women. This guidance draws on previous guidance detailed in the reference list, including from the UN Evaluation Group (UNEG)¹, the UN Ethics Office¹⁰, as well as accepted international ethical standards with which all researchers and ethical committees are expected to comply when engaged in health research¹¹ and research with people with disabilities.¹²

OVERARCHING PRINCIPLES

Four key overarching principles outlined below should be upheld throughout the research and evaluation process:

- 1. Informed consent.** All participants must be fully informed as to what is being asked of them, including the topics discussed, who is involved, how data they provide will be processed and stored, and potential risks and benefits, so that they can make a fully informed decision about whether they wish to participate.
 - a.** It is recommended to obtain informed consent in a format that is accessible to the individual concerned, for example either a signed form or an audio recording of their verbal consent as evidence of informed consent – see section on 'Accessibility' below for more information on capacity and accessibility.
 - b.** Informed consent also emphasizes that participation in the project is voluntary. This should be clarified in preliminary discussions with local stakeholders, and should continue throughout the recruitment and consent process, into data-collection procedures.
 - c.** It should be made clear to all women and girls with disabilities that they may decline to join the study altogether, that they may decline to answer specific questions in a survey or interview, and that they may withdraw from the study at any point.
 - d.** It must also be affirmed that participation or declining participation in the study will not have any negative impact on continued access to services,¹³ particularly in cases where an organization (e.g., United Nations, local ministry, or local OPD or NGO) is supporting a study and is also providing a service to women and girls with disabilities, to avoid the risk of coercion and/or undue influence.

2. Benefit, not harm. There is a risk of potential psychological distress arising from sensitive questions being asked while engaged as a participant in the project.

- a.** Risk of harm to participants arising from investigating stigma, discrimination, gender-based violence (GBV) and other sensitive experiences must be balanced with the potential benefit to the overall community and must be minimized wherever possible throughout. This will be done during the conceptualization phase through the selection of appropriate questions and wording, as well as during the implementation phase, by ensuring the privacy and confidentiality of respondents, training of data collectors on issues such as verbal and non-verbal communication (active listening, validating, non-judgemental stance) and ethical and safety principles and mechanisms, and how to manage any distress observed during data collection.
- b.** In addition, establishing the availability of appropriate support structures for women and girls with disabilities who may need them (i.e., to provide appropriate signposting and/or referral to relevant support systems where available, or what to do when such supports and services may not be in existence).^{14, 15}
- c.** Data collectors should also be protected from harm. Throughout the planning and implementation process, consideration should be given to their training and support needs as they may hear information that could be distressing to them. Mechanisms for ensuring their protection will be further discussed and agreed upon while supporting the training of data collectors in each participating country.

3. Confidentiality. All participants have the right for their participation to remain confidential in that only the data collectors and persons they choose to inform (e.g., perhaps the person from an OPD who informed them about the project or trusted caregiver who they wish to accompany them) will be aware that they have participated. Appropriate measures must be put in place to make certain that the information participants have shared, and their identity, are kept confidential. This is particularly important for personal and sensitive data about women and girls with disabilities who are often at increased risk of discrimination and violence based on their disability and gender, and who may be disclosing sensitive information in relation to GBV. As such, recruitment via word of mouth

and using organizations' existing networks and collaborations may be more appropriate to ensure the privacy of participating women and girls with disabilities than, for example, public advertising of information about the project. Additionally, to ensure privacy, women and girls with disabilities should have the option to disclose, or withhold, information about their personal characteristics. Questions about personal characteristics should be voluntary and a non-response option should be provided. Categorizing responses to such questions can support confidentiality (e.g. asking for age in age groups or ranges rather than in specific numbers).¹⁶ Ensuring confidentiality includes how the data are collected (e.g. making sure that the interview location is private), how the data are stored (e.g. with names and other identifiers removed), and how the data about women and girls with disabilities are shared.¹³ Country offices must follow retention policy guidelines for their office for the safekeeping and/or disposition of all records and documents.¹³ Any personal data should only be used for purposes of analysis and be aggregated in a way that does not allow for the identification of individuals, for example by aggregating the data via subgroups.^{8,13}

4. Data protection/Data transfer. Countries should comply with internationally accepted regulations and good practice standards in the collection, storage, analysis and reporting of data. Data protection legislation and procedures may vary significantly across countries, but all country offices and local stakeholders should ensure that:⁸

- a.** Data are processed in a transparent, fair and lawful manner.
- b.** Data are collected for explicit, specific and legitimate purposes
- c.** The processing of the data is necessary and limited to the legitimate stated purpose
- d.** Data are adequate, relevant, accurate, up-to-date and fit for the purposes of data processing
- e.** The confidentiality of data is protected with appropriate measures that prevent unauthorized access, destruction, use, modification or disclosure
- f.** Data processors are accountable for any breach of the above principles (and must report all data breaches within 24 hours to the respective country office)
- g.** Data subjects (i.e., participants) are granted the right to receive information about the data being collected and stored, to rectify incorrect or outdated information and to request the deletion of data that are unlawfully stored.

ALIGNMENT WITH THE UN EVALUATION GROUP'S ETHICAL PRINCIPLES

This guide is in line with the UN Evaluation Group's four ethical principles for evaluation:¹

1. Integrity, where truthfulness, professionalism and independence, impartiality and incorruptibility are followed to mitigate any conflicts of interest or bias. Ongoing reflective practice is encouraged.

2. Accountability.

- a.** *Transparency* of the coordination of the national rollout and accountability to all stakeholders (national and international) is key. Roles, responsibilities and reporting relationships need to be made clear wherever partnerships or alliances exist with OPDs or ministries, to minimize the risk of conflicts of interest.
- b.** *Responsiveness* to the methodology of tools and interventions as questions or feedback arise and, given that addressing GBV is a goal of this project, referring individuals to appropriate channels where sexual exploitation, abuse or other misconduct are identified is key.
- c.** *Taking responsibility* for reporting potential or actual harms observed through the appropriate channels.
- d.** *Justifying* and fairly and accurately reporting to stakeholders (including women and girls with disabilities) decisions, actions and intentions through the co-production of material and summary reports. As part of a human rights-based approach, emphasis is placed upon transparency in the use of data to ensure accountability in policy implementation and enhance the capacity of women and girls with disabilities to engage in policy design and implementation.⁸

3. Respect.

- a.** *Respect for persons*, which relates to respecting the autonomy and self-determination of participants, and protecting those who lack autonomy, including by protecting them from harm.
- b.** *Access* to the process and outputs by all relevant stakeholders by ensuring accessible versions of material and reports.
- c.** *Meaningful engagement and fair treatment* of all relevant stakeholders, particularly women and girls with disabilities, in the evaluation processes from design to dissemination, so they can actively inform the evaluation approach and products rather than being solely a subject of data collection.
- d.** *Fair representation* of different voices and perspectives in evaluation by ensuring that intersectionality is captured and making adaptations to materials wherever possible.

4. Beneficence.

- a.** *Explicit and ongoing consideration of the risks and benefits* of taking part and considering longer-term consequences.
- b.** *Maximizing the benefits* of the project at systemic (including institutional), organizational and programmatic levels.
- c.** *Doing no harm* and not proceeding in situations where harm cannot be mitigated.
- d.** *Ensuring that evaluation makes an overall positive contribution* to the wider community and to the mission of the United Nations.

KEY CONSIDERATIONS

In addition, guidance is presented below on four key considerations throughout the process to ensure the safe and meaningful participation of women and girls with disabilities throughout the research and evaluation process.

1. Accessibility

Providing support to enable persons with disabilities to participate meaningfully includes measures relating to universal design and accessibility.¹⁷ Universal design enables multiple formats for data collection and information-giving, changing the setting or format to accommodate participants,¹⁸ (e.g., by having questions and response options read out by the survey software used, to overcome the need for literacy). Research materials should be further elaborated and adapted in collaboration with women and girls with disabilities. More detailed guidance on accessibility considerations for persons with intellectual disabilities is available in the ‘Listen, Include, Respect’ International Guidelines for Inclusive Participation.¹⁹

Article 12 of the CRPD affirms that all adults with disabilities enjoy legal capacity (i.e., the ability to hold and exercise rights and duties) on an equal basis with others in all aspects of life. The CRPD Committee General Comment 1 denotes that under Article 12, perceived or actual deficits in mental capacity should not be used as justification for denying legal capacity.¹⁷ Persons with disabilities should be given access to support to exercise capacity and decision-making.¹⁷ The UN General Assembly Special Rapporteur’s report on legal capacity²⁰ set out means of supported decision-making (see paras 27–33). It also noted that women with disabilities are at a particularly high risk of substitute decision-making (where a substitute decision-maker appointed by a third party takes decisions based on what he or she considers to be in the best interests of the person concerned, even if it goes against the will of the latter) owing to gender stereotypes and GBV. The GBV Disability Toolkit²¹ outlines ways of determining informed consent with survivors and what to do in situations where it is difficult to ascertain this. Standard operating procedures are encouraged in each country office to determine this.

The overall scope of the ASDWD project was focused on women and girls with disabilities. Of note though, laws concerning capacity and consent in many countries make different provisions for minors. As such, if girls with disabilities are to be involved as participants, the evolving capacities of children with disabilities (see CRPD Article 3[h]) must be considered carefully, as well as local legal provisions regarding research with minors. Further ethical and methodological considerations are provided in the UNICEF Working Paper on the Involvement of Children with Disabilities in Evidence Generation and Use.²²

The active and meaningful participation of people with disabilities, through their representative organizations, is at the heart of the CRPD²³ – accordingly, people with disabilities should participate in the design of research, evaluation and policies.⁸ The UN Disability Inclusion Strategy Guidelines on Consulting Persons with Disabilities⁶ provide in-depth guidance on why, when and how best to engage women and girls with disabilities and their respective organizations. All stakeholders of the ASDWD project who will be engaging with women and girls with disabilities and OPDs should familiarize themselves with these guidelines.

2. Safety

Safeguarding measures need to be put in place to ensure the safety and privacy of both participants and data collectors. The focus of the survey should be kept on stigma and discrimination in information sheets and discussions with participants (i.e., not specifically mentioning GBV). Ensuring the privacy and safety of the setting in which data collection takes place is key. This should be agreed upon with the participant. Some women and girls with disabilities may choose to have a trusted caregiver or family member present with them during their participation. Participants should be asked in advance and in private regarding their preferred arrangement. If they do choose to have someone present,²¹ care should be taken to ensure that the research process does not interfere with the relationship between the participant and her supporter or caregiver.¹¹

3. Signposting to appropriate resources

Country offices are responsible for putting together a list of resources and organizations available to women and girls with disabilities who participate in the ASDWD project and disclose safeguarding issues. Those collecting data from women and girls with disabilities are responsible for offering information on available resources and supports to respondents who wish to and who feel safe in receiving this information – data collectors should be provided with such information during training and have an opportunity to practice managing potential distress presented by a participant.

4. Making ethical decisions

While keeping these frameworks and guidance in mind for ethical implementation, there may be times when stakeholders are faced with difficult decisions. For example, if a woman with a disability discloses information that highlights that she is currently at risk of harm of violence, sexual exploitation or abuse. This poses an ethical dilemma as it may not be possible to honour confidentiality and serve the best interests of the survivor. The World Health Organization provides ethical and safety [recommendations](#) for research involving violence against women, which all data managers should become familiar with.¹⁴ All UN personnel and individuals involved in recruitment and data collection must familiarize themselves with the Inter-Agency Standing Committee's Minimum Operating Standards for Protection from Sexual Exploitation and Abuse.²⁴ A six-step model outlined by the UN Ethics Office¹⁰ helps data collectors and managers to think through difficult scenarios such as these. In addition, as well as considering the unique individual, family, community, cultural and spiritual setting in which the survivor is based, data collectors and managers must familiarize themselves with relevant country- and organization-specific guidance on supporting survivors of GBV and advice should be sought from local disability and GBV experts. It is good practice to establish standard operating procedures for confidentiality in each country office prior to data collection.

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The Ethical guidance was used throughout the UNDP and UN Women Joint Project “Addressing Stigma and Discrimination Experienced by Women with Disabilities” (ASDWD) to minimize the risk of harm while engaging women with disabilities. The human rights-based approach and the ‘Do No Harm’ principle guided the conceptualization and implementation of these guidelines.

