







METHODOLOGICAL NOTE

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The Women with Disabilities Stigma Inventory (WDSI) was developed by researchers from University College London (Katrina Scior, Aseel Hamid and Amy Dixon) in close partnership with the UNDP and UN Women personnel and representatives of organizations for people with disabilies and non-governmental organizations and their female members with disabilities in four pilot countries: Pakistan, Palestine, Republic of Moldova, and Samoa. This methodological note was produced by the research team, with statistical support from Rob Saunders and Henry Delamain at University College London.

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METHODOLOGICAL NOTE WOMEN WITH DISABILITIES STIGMA INVENTORY (WDSI) 1.0



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OVERVIEW

The purpose of this document is to provide an overview of the Women with Disabilities Stigma Inventory (WDSI) 1.0., its development process and how to implement the tool and analyse results.

The Women with Disabilities Stigma Inventory (WDSI) was developed as part of the project "Addressing Stigma and Discrimination Experienced by Women with Disabilities" (ASDWD), which was jointly 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 (UN PRPD). The project was conducted in partnership with local organizations of people with disabilities, and women with disabilities who contributed across the four project countries: Pakistan, Palestine, Republic of Moldova and Samoa.

The ASDWD project focused on the intersection of disability and gender-based stigma and discrimination. A key objective was to create a survey tool to assess the experiences of women and girls with disabilities regarding stigma, discrimination and gender-based violence. To this end, alongside developing the WDSI using a participatory approach, ethical guidelines and a detailed guide for data collectors were also produced to ensure a human-rights-based approach and minimize harm.

This document presents methodological information about the WDSI, as a stand-alone self-reporting survey tool that can be used to collect data about the experiences of women with disabilities globally.

For more information, please see the following documents:

- WDSI 1.0
- Ethical Standards Guide for the ASDWD project
- UN Policy Paper: <u>Addressing Stigma and</u> <u>Discrimination to Eliminate Violence against</u> <u>Women with Disabilities.</u>

1. DEVELOPMENT OF THE WOMEN WITH DISABILITIES STIGMA INVENTORY

The development of the draft version of the WDSI underwent four stages before the fifth iteration of the tool was used for field testing. Initially, a large item pool was created by the research team, informed by a desk review of measures designed to assess stigma related to disability, evidence in the literature on key concerns for women and girls with disabilities, and relevant existing measures.

Existing literature that was cited or used to inform the WDSI includes the following:

- Ciocan. 2021. Moldova Survey for People with Disabilities.
- Curry et al. 2009. Safer and Stronger Program.
- Firmin et al. 2017. Stigma Resistance Scale.
- Friedland et al. 2020. People Living with HIV Stigma Index 2.0.
- McFarlane et al. 2001. Abuse Assessment Screen-Disability.
- Washington Group on Disability Statistics. 2020. Washington Group Short Set on Functioning.

The item pool was reviewed and refined in close partnership with the four UN Country Teams, their local partner organizations and women with disabilities affiliated with them, at each stage of development. An early draft version of the tool was then piloted with 5 to 10 women with disabilities in each of the four pilot countries. Feedback was received from participants and data collectors on both the content and wording. Comments and suggestions were integrated into a revised version, which was again shared for comments with each Country Team. Feedback was sought through written communications and regular webinars.

Identification of potential items:

Generation of Version 1 of the Tool:

Consultants generate initial domains and a large

Review of Version 1 of the Took:

3-5 local experts, identified by the in-country teams, invited to comment on the draft item pool

Review of Version 2 of the Tool:

Local experts review changes to version 2 prior to

Translation of Version 2:

- In-country teams identify 2 individuals for the translation and back translation of the item pool into the local language(s)
- Draft item pool translated into local language(s)

Second review of Version 2 of the Tool:

- Local experts check the tool before it is shared
- Local partners consult approx. 2 groups of women with disabilities about the draft item

Review and Translation of Version 3 of the Tool:

- Local experts review changes to version 3 prior to
- In-country teams translate the tool and check the translation before field testing

Pilot:

- In-country teams conduct initial testing and rollout of the tool with 5-10 women with disabilities (per country)
- -In-country teams collect and share feedback on

Review and translation of Version 4:

- Local experts review changes to version 4 prior to
- In-country teams translate the tool and check the translation before the pilot

Field testing of Version 5:

In-country teams conduct initial pilot of the tool

Final Tool (WDSI 1.0): Knowledge product

Note: The final iteration of the tool post-field testing is named WDSI 1.0.

The process of developing the WDSI, from design through to field testing is presented in Figure 1.

Post-feedback adaptations:

- Consultants evaluate the outcome of the
- Appropriate changes made to the item pool and domains

Post-feedback adaptations:

Consultants examine the equivalence of the

Post-feedback adaptations:

- Consultants evaluate the outcome of the
- Appropriate changes made to the item pool and domains
- Tool customized for country-level plots
- Version 3 of the tool is produced

Post-feedback adaptations:

- Consultants evaluate the feedback
- Appropriate changes made to the item pool and domains
- Tool customized for country-level pilots

Feedback from field testing:

Data Analysis:

- evaluate the psychometric quality of the tool Appropriate changes made to the item pool and domains based on the results

1.1 Translation and customization for countrylevel implementation

The WDSI draft versions were translated from English into the local languages, then back-translated by professional translators. The research team then checked for semantic equivalence with the original English version and in discussion with the country teams made adaptations to items where concepts did not translate well.

While retaining a common item pool, the wording of individual questions and response options was carefully tailored to the local cultural and religious context, where indicated. For example, in Moldova and Samoa, the term 'partner or husband' was used, whereas in Pakistan and Palestine only 'husband' was used.

In Moldova, at the request of the UN Country Team, additional questions were added about access to justice and support for victims of violence. These are included in the WDSI 1.0 (Section 5).

Questions about the impact of the COVID-19 pandemic were included in early versions but during later field testing were only implemented in one of the project countries. These questions have been omitted from the WDSI 1.0.

1.2 Involvement of women with disabilities

Women with disabilities were involved throughout the development and testing of the tool, in the role of local consultants, focus group and pilot testing participants, data collectors and participants in the field testing. Focus groups were held in each country by the local partners early on in the development process to secure feedback on the draft item pool, identify potential gaps and assess the face and content validity of the WDSI. Women with disabilities were also asked to provide feedback about the tool during piloting. Their feedback and concerns were integrated into subsequent revisions of the tool.

1.3 Ethical issues

Ethical approval for the project was granted by the University College London Research Ethics Committee. In addition, approval for field testing in each country was granted by the relevant government department. The imperative to minimize the risk of harm and safeguard potential participants led to the formation of a dedicated working group that produced detailed ethical guidance for the project.

2. FIELD TESTING OF THE WDSI

The draft version of the WDSI used for field testing was a common set of 79 items, in some instances supplemented by a brief set of items requested by the UN Country Team (see 1.1 above).

2.1 Participants in the field testing

Participants were women aged 18+ with different types of disabilities and the capacity to consent to take part. Due to ethical considerations, only women in the following groups were recruited for field testing: those registered as disabled on national disability registers, women already known to organizations of people with disabilities, and/or suggested by another participant.

Sample sizes differed between countries, largely due to different data-collection methods and also very adverse conditions affecting the project, particularly in Pakistan (extensive and prolonged flooding) and Moldova (impact of the conflict in neighbouring Ukraine).

TABLE 1

Overview of samples for field testing of the WDSI

Country	N
Moldova	110
Pakistan	93
Palestine	337
Samoa	127
Total	667

Based on responses to the Washington Group Short Set on Functioning (WG-SS), the most frequently reported disability across the sample was 'difficulty walking' (n=224; 33.4% of the sample), followed by 'difficulty seeing' (n=127, 19%), 'difficulty with selfcare' (n=97, 14.5%), 'difficulty hearing' (n=80, 11.9%), 'difficulty remembering' (n=76, 11.3%) and 'difficulty communicating' (n=68; 10.1%). Across all samples, most women reported that their difficulties were visible to others (n=495; 73.9%), being in possession of a disability registration card (n=435; 64.9%), and using some form of assistive device (n=350, 52.2%).

2.2 Procedure for field testing

Data collection in the four partner countries was conducted between September 2022 and February 2023. The recruitment of participants and data collection were conducted by the UNDP and UN Women offices' local stakeholders, namely: Moldova: Motivatie Association; Pakistan: HANDS (Sindh) and Women's Welfare Association (Balochistan); Palestine: Social workers from the Ministry of Social Development and the Ministry of Women's Affairs; and Samoa: Nuanua O Le Alofa (NOLA). In Moldova and Samoa, recruitment and data collection were conducted at the national level; in Pakistan, the provinces of Balochistan and Sindh were targeted; and in Palestine, data were mainly collected in the West Bank, with some additional telephone interviews conducted with participants from Gaza.

A range of methods were utilized for field testing, including one-to-one interviews, face-to-face, by telephone and online. Interviews were conducted in a private room in participants' homes or at the office of an organization for people with disabilities, or community site. In a small number of cases, where a signage interpreter was not available to support women with hearing or speech impairments, with participants' consent a family member attended the meeting instead. The tool was available in paper format and as an online Qualtrics survey, with six language versions (English, Arabic, Russian, Romanian, Samoan and Urdu). Key terms were defined and explained by data collectors throughout. Enumerators (i.e. data collectors) were encouraged to make necessary adaptations to the administration of the interview to ensure that it was accessible to participants.

In most cases, enumerators entered data in real-time into Qualtrics, using mobile devices. In other cases, the data were entered subsequently and carefully checked for data entry errors.

Following completion of the WDSI, participants were provided with information on local services where they could seek support for issues covered in the WDSI.

2.3 Enumerator training

Prior to data collection, all enumerators attended training focused on familiarizing them with the WDSI and building their skills to administer the survey. This included an overview of the project goals, ethical considerations like ensuring privacy and confidentiality during interviews, building rapport with participants, and ensuring that the enumerators knew where to seek support should the interview be upsetting for them or the participants. To support and reinforce the training, trainers and enumerators were provided with guidance for data collectors and an ethical standards guide (see separate documents).

2.4 Analysis of field testing data

Data from the four project countries were analysed at country level and also processed and harmonized by the central research team, based at University College London (UCL).

Sections 1, 2 and 5 of the WDSI (respectively sociodemographic data, disability/functioning-related data, and experiences of discrimination and violence) are designed for the purposes of gathering descriptive data, and as such field-testing data for these sections were not subjected to psychometric analyses. Data for WDSI sections that use four-point Likert scales of never/rarely/sometimes/often (Sections 3, 4, 6 and 7, respectively on Exclusion and marginalization; Experiences of abuse; Responses to

stigma and discrimination; and Rights and effecting change), were analysed as follows: initially, Cronbach's α (as a measure of internal consistency) was calculated for each of these sections. Items correlating with other items >0.80 were identified as potential candidates for removal, due to possible redundancy. Decisions about item removal were made after careful consideration about item phrasing, the amount of 'missingness' (when no data value is stored for the variable in an observation) and correlation with multiple items.

To determine the number of underpinning factors for each of these sections, or parts thereof, exploratory factor analysis (EFA) was conducted with the eigenvalue >1.0 threshold to determine unique factors. Items in these sections were processed as ordinal categorical items and polychoric correlations were calculated between them. Cronbach's α was then recalculated for the identified factors.

2.5 Results of analysis of field testing data

The results of analyses of field testing internal consistency and factor analyses are reported below.

2.5.1 Results for Section 3: Exclusion and marginalization

Three of the 12 items included in the field testing version ('denied bank account'; 'excluded from religious activities'; and 'denied access to public transport') were highly correlated with other items and removed. EFA was then performed, with only one eigenvalue >1.0 (4.67), indicating that a single-factor solution best fit the data. Cronbach's α was recalculated for this nine-item factor solution with good reliability achieved (α = 0.84). Table 2 presents the nine factor loadings.

2.5.2 Results for Section 4: Experiences of abuse

For this section, two of 10 items included in the field-testing version ('teased by strangers' and 'prevented from using assistive device') were highly correlated with other items and removed. EFA was then performed, with only one eigenvalue >1.0 (4.46), indicating a single-factor solution as the best fit for the data. Cronbach's α was recalculated for this eight-item factor solution with good reliability achieved ($\alpha = 0.85$). Table 2 presents the eight factor loadings.

2.5.3 Results for Section 6: Responses to stigma and discrimination

For this section, three of the nine items included in the field testing version ('you can have a good, fulfilling life, despite your difficulties'; 'you tell yourself positive things to help you stand up to prejudice and discrimination'; and 'when you experience prejudice and/or discrimination, you think of positive things about yourself') were highly correlated with other items and removed. EFA was then performed, with only one eigenvalue >1.0 (3.60), indicating a single-factor solution. Cronbach's **a** was recalculated for this six-item factor solution with good reliability achieved (**a** = 0.85). Table 2 (below) presents the six factor loadings.

2.5.4 Results for Section 7: Rights and effecting change

Items assessing awareness of a range of human rights were subjected to factor analytic procedures to decide whether to sum these or report them individually. The decision was made to retain these as individual items. For the questions regarding effecting change and help with rights, one of the six items ('participated in discussions about laws and policies about improving the lives of people with disability') was highly correlated with other items and removed. EFA was then performed, with only one eigenvalue >1.0 (2.99), indicating a single-factor solution. Cronbach's **a** was recalculated for this five-item factor solution with good reliability achieved ($\alpha = 0.717$). Table 2 presents the five factor loadings.

TABLE 2 Individual scale factor loadings

Exclusion and marginalization		Experiences of abuse		Responses to stigma and discrimination		Rights and effecting change	
Item	Loading	ltem	Loading	Item	Loading	ltem	Loading
Denied education opportunities	0.659	Teased, laughed at, gossiped about (by close relations)	0.763	Can have positive view of self, even when others don't	0.805	Family/friends helped you stand up for your rights	0.527
Denied employment	0.519	Verbally abused (by close relations)	0.821	Know prejudice and discrimination is wrong	0.662	Community leaders/ organizations helped you stand up for your rights	0.812
Denied access to computer/Internet	0.677	Physically abused (by close relations)	0.782	Able to confront prejudice and do what you want to do	0.733	Easy to access leaders/ officials to discuss rights-based issues	0.814
Denied mobile phone	0.730	Stolen from or had possessions destroyed (by close relations)	0.753	Aware of personal strengths	0.834	Opportunities to challenge unfair treatment or educate others	0.526
Excluded from social gatherings or activities	0.838	Forced to be in room/ house alone	0.640	Remind yourself that you are not defined by difficulties/disability	0.794	Participated in disability rights advocacy	0.646
Excluded from family activities	0.841	Verbally abused (by strangers)	0.787	Challenge negative thoughts about your difficulties	0.807		
Denied access to health care	0.734	Physically abused (by strangers)	0.741				
Denied access to public services	0.757	Stolen from or had possessions destroyed (by strangers)	0.666				
Avoided by others	0.674						

3. QUESTIONS INCLUDED IN THE WDSI 1.0

Following revision in line with the analysis of field testing data, the WDSI 1.0 contains 42 main questions, some with supplementary questions and follow-up items. The items are organized into seven distinct sections, as detailed below.

Section 1. About you: Eight items (one with optional subquestions), gathering sociodemographic information about participants, including age group, living environment (rural/semi-rural/urban), ethnicity, relationship status, children, others in home, education, work status, membership in other marginalized group (e.g. refugee, member of religious minority, etc.).

Section 2. Disability: Six items corresponding with the Washington Group Short Set on Functioning (WG-SS). The WG-SS was designed to identify difficulties in functioning that may put a person at risk of limited or restricted participation. That risk of restricted participation, in the absence of accommodations, is a 'disability', as defined by the UN Convention on the Rights of Persons with Disabilities (CRPD). The items concern difficulties with seeing, hearing, walking, remembering or concentrating, self-care or communication.

These items were supplemented with five questions regarding whether these difficulties are visible to others, whether assistive devices and other supports are needed, and whether respondents have disability registration/an identity card.

Section 3. Experiences of exclusion and marginalization: Nine items, using a 4-point Likert scale ('never' to 'often' plus 'prefer not to say'); one follow-up item to identify perpetrator/s of any exclusion/ marginalization experienced; three items to explore the perceived impact of intersectional, potentially stigmatized identities/attributes (disability, gender and other attributes) on experiences of exclusion and marginalization, using the same 4-point Likert scale, plus 'don't know', and one open-ended question asking about other experiences the respondent would like to share. Section 4. Experiences of abuse: Eight items, using the same Likert scale as Section 3; two follow-up questions to identify perpetrator/s; and three follow-up items to explore the perceived impact of disability, gender and other attributes on experiences of abuse.

Section 5. Experiences of discrimination and violence: Five items using 'yes', 'no', 'don't know', plus 'prefer not to say' and, where indicated, follow-up questions to identify perpetrator/s; three items to explore the perceived impact of disability, gender and other attributes on experiences of discrimination and violence; and one item regarding support accessed. This section also asks about the perceived extent to which a range of agencies support women with disabilities who experience violence and where respondents would turn for help or assistance were they to experience violence. While these latter questions are not immediately about personal experiences, they were deemed important by the UN partners to identify potential gaps in responses to violence.

Section 6. Responses to stigma and discrimination: Six items assessing to what extent participants are able to maintain a positive view of self and resist stigma, using a 4-point Likert scale ('never' to 'often').

Section 7. Rights and effecting change: 11 items assessing awareness of rights, rated on a 3-point Likert scale ('not at all aware' to 'very aware'); five items regarding support in advocating for rights, using a 4-point Likert scale ('never' to 'often'); plus two open-ended questions regarding opportunities to learn about rights and past engagement in advocacy. The WDSI 1.0 sections, existing tools which items were based on or informed by, and guidance for scoring are summarized in Table 3. The tool itself is available as a separate document.

TABLE 3 WDSI sections and subscales

Subscale	Number of items	Response options	Scoring	Measures used to inform items
1. About you	8	See WDSI 1.0	For descriptive purposes	
2. Disability (a) limitations in functioning	6	4-point Likert scale ('no difficulty' to 'cannot do at all')	1 = yes, disability present in this area of functioning: 'a lot of difficulty' or 'cannot do at all'; o = no disability in this area: 'a little difficulty' or 'no difficulty'	Washington Group on Disability Statistics. 2020. Washington Group Short Set on Functioning
(b) Further details	5	'yes', 'no', 'don't know', 'prefer not to say'	1 = yes; 0 = no or 'don't know'	
3. Experiences of exclusion and marginalization	9	4-point Likert scale ('never' to 'often' + 'prefer not to say')	Score individual items as $o = never$; $1 = rarely$; $2 = sometimes$; $3 = often$. If desired, calculate a mean subscale score ($o - 3$)	Friedland et al. 2020. People Living with HIV Stigma Index 2.0
4. Experiences of abuse	8	4-point Likert scale ('never' to 'often' + 'prefer not to say')	Score individual items as $o =$ never; $1 =$ rarely; $2 =$ sometimes; $3 =$ often. If desired, calculate a mean subscale score ($o - 3$)	McFarlane et al. 2001. Abuse Assessment Screen-Disability Curry et al. 2009. Safer and Stronger Program
5. Experiences of discrimination and violence	5	'yes', 'no', 'don't know', 'prefer not to say'	Score individual items as $o = no/don't$ know; 1 = yes. If desired, calculate the sum of scores (o – 5)	McFarlane et al. 2001. Abuse Assessment Screen-Disability Curry et al. 2009. Safer and Stronger Program
6. Responses to stigma and discrimination	6	4-point Likert scale ('never' to 'often')	Score individual items as $0 =$ never; $1 =$ rarely; $2 =$ sometimes; $3 =$ often. If desired, calculate a mean subscale score ($0 - 3$)	Firmin et al. 2017. Stigma Resistance Scale
7. Rights and effecting change (a) Awareness of rights	11	3-point Likert scale ('not at all aware' to 'very aware')	2 = very aware, 1 = a little aware; o = not at all aware. If desired, calculate the sum of scores ($o - 22$)	Ciocan. 2021. Moldova Survey for People with Disabilities.
(b) Effecting change	5	4-point Likert scale ('never' to 'often')	O = never; 1 = rarely; 2 = sometimes; 3 = often. If desired, calculate a mean subscale score (O - 3)	

Note: Responses of 'prefer not to say' are not scored and should be reported separately.

4. ADMINISTRATION, SCORING AND INTERPRETATION

4.1 Administration

The WDSI 1.0 can be self-administered by the respondent or administered in a face-to-face, telephone or online interview. Administering the WDSI as an interview typically takes 45 to 60 minutes but may take longer. The time required for self-administration should be shorter but has not been measured.

Self-administering the survey tool does not require any instructions other than those given in the survey.

Where the WDSI is administered through interviews, the separate *Guidance for Data Collectors* should be referred to.

4.2 Scoring

In many instances, users of the WDSI may want detailed descriptive data to document the experiences and concerns of women with disabilities and identify priorities for policy and/or intervention. In such cases, it is appropriate to summarize the raw data.

For more in-depth analyses, such as to relate sociodemographic variables to scores on different subscales or to compare scores from two different populations, information for scoring of items and subscales is provided in Table 3. Items set out in Table 2 can be scored and analysed as subscales, e.g. to evaluate changes over time or to compare different samples. Where data are missing for more than one item in a subscale (i.e. 10 per cent or more of data missing), it is recommended not to calculate a mean or summary score or to use a multiple imputation method.

4.3 Interpreting the results

Careful attention must be paid to the meaning of the scoring, summarized in Table 3.

Section 2, which uses the Washington Group Short Set on Functioning, is scored in line with instructions

set out in 2020 by the Washington Group on Disability Statistics. Accordingly, a score of 1 (indicating the presence of disability in the respective area of functioning) is given for responses of 'a lot of difficulty' or 'cannot do at all'. A score of o (indicating no disability) is given for responses of 'a little difficulty' or 'no difficulty'. For the follow-up questions (items 10 to 14), a score of 1 indicates greater need for disability support or visibility of the disability to others.

For items in **sections 3 and 4** that use 4-point Likert scales, a score of o or 1 indicates that the negative experience referred to never or rarely occurs, while a score of 2 or 3 indicates that it occurs sometimes or frequently. Follow-up questions are interpreted for information purposes.

For **section 5**, any response of 1 = yes to items detailing discrimination or violence indicates that a negative event has occurred. Follow-up questions and responses to questions 35 and 36 (regarding support for women who experience violence) are interpreted for information purposes.

For **section 6**, scores of 2 or 3 indicate that the respondent is able to maintain a positive view of self and resist stigma, while scores of 0 or 1 indicate that this is never or only rarely the case.

For **section 7**, awareness of individual rights and notable gaps therein may be just as instructive as summing scores to indicate an overall awareness of rights, with scores of 2 indicating a lot of awareness, 1 some awareness, and o no awareness of the respective right. Follow-up questions are interpreted for information purposes.

Of note, responses of 'prefer not to say' should be noted as they may well indicate that respondents experience particular sensitivities or shame relating to the question or are too afraid to report instances of exclusion and abuse.

5. STRENGTHS AND LIMITATIONS OF THE WDSI 1.0

The WDSI assesses the experiences of women with disabilities through their first-hand accounts. It does not seek to triangulate or confirm their responses by also gathering data from third-person informants.

The WDSI's comprehensiveness as a survey tool is one of its strengths but also a key limitation, as it means the tool generates a broad, overall picture of experiences of stigma, discrimination and violence faced by women with disabilities. Those seeking more detailed information about specific areas covered in the WDSI may wish to supplement it with other more specific tools, or to use such tools from the outset. The WDSI needs to be validated with larger samples and in other cultural settings. Further studies need to be done to assess the psychometric properties of the WDSI and its subsections and to inform future revisions of the tool.

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The purpose of this methodological note is to provide an overview of the Women with Disabilities Stigma Inventory (WDSI) 1.0., its development process and how to implement the tool and analyse results. The Women with Disabilities Stigma Inventory (WDSI) was developed as part of the project "Addressing Stigma and Discrimination Experienced by Women with Disabilities" (ASDWD), which was jointly 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 (UN PRPD).





