Existing evidence indicates that disability is a risk factor for violence against women, and disability status also may influence dynamics and patterns of violence against women, including the types of violence women are subjected to and perpetrators that commit violence against women. Literature reviews, systematic reviews and comparative data analyses focusing on violence and disability have indicated that adults with disability are at greater risk for exposure to violence [1-3]. Yet, significant limitations remain in current understanding of the relationship between disability and violence against women, including that some analyses do not adequately account for sex and gender and their shaping of vulnerability to violence.

As part of the UN Women-WHO Joint Programme on Strengthening Methodologies and Measurement and Building National Capacities for Violence Against Women Data (Joint Programme on VAW Data), WHO/HRP has been leading work to strengthen the measurement of disability and violence against women. WHO/HRP undertook a scoping review to explore how disability and violence are currently being measured in the existing evidence-base [4]. In November 2022, WHO/HRP convened this Expert Group meeting (the Meeting agenda is included as Annex 1). Technical and advocacy experts participated in the meeting, including women with disabilities (List of participants is Annex 2), to develop concrete recommendations for approaches and measures to better capture the experiences of violence among women with disabilities.

The objectives of the Expert Meeting on Violence against Women and Disability were:

- To provide a forum for in-depth discussion of measurement and methodological issues related to generating internationally comparable data and evidence on violence against women with disabilities;
- To discuss the strengths and limitations of current methodological and measurement approaches to assessing the prevalence and nature of violence against women living with disabilities; and
- To develop recommendations for rigorous measurement of violence against women with disabilities in surveys and other approaches.

This meeting summary compiles key points from the presentations and discussions at the Expert Meeting. Key recommendations developed during the Expert Meeting are included following the summary.
1. Sources, availability, and quality of data on violence against women with disabilities

Dr. Morgan Banks, from the London School of Hygiene and Tropical Medicine in the United Kingdom of Great Britain and Northern Ireland, presented an overview on the existing data and evidence on violence against women with disabilities. Sources of data on prevalence of violence against women and disability include:

a) Demographic and Health surveys [DHS], which can include domestic violence modules and the Washington Group Short Set [WGSS] questions,
b) Multiple Indicator Cluster Surveys [MICS], which include violent discipline towards children 2-14 year old and child marriage, and women and men's attitudes towards domestic violence,
c) Violence against Children Surveys [VACS], of which only those from Lesotho and Moldova include data on disability, and
d) other national and sub-national surveys.

DHS data shows that across eight countries, women with disabilities are more likely to have been subjected to intimate partner violence [IPV] in the past 12 months. MICS data also indicates that children with disabilities are more likely to experience violent discipline and severe punishment by disability status.

Existing systematic reviews [1, 5, 6] indicate consistently elevated risk of violence for persons with disability, however, none of these reviews are disaggregated by sex, primarily due to the lack of disaggregated data within studies. Despite an overall increase in data on women with disabilities, there is a need for higher quality data (for example, tracking trends over time), and there is still very limited data on differences in prevalence of violence by type of disability, wealth and age, impact of violence, and women with disabilities' experiences seeking justice and support services. Differing definitions and measures of violence against women across surveys and countries makes comparability of results challenging. Factors affecting the quality of data on women with disabilities includes sampling and non-inclusive data collection practices. Sample sizes are often not large enough to disaggregate by disability. Surveys rarely include people who are street connected, incarcerated or living in residential care, and women with disabilities are likely over-represented in these groups. DHS interviewer’s manual and training field staff manual have no mention of disability or of providing accommodations to support self-reporting. Some surveys, for example, the VACS, excludes children with “severe physical or mental disabilities,” including children who cannot communicate “in the language of the survey.”

Producing more and higher quality data on violence against women with disabilities requires considering disability during the design of the study, including which measures to select, sample sizes and sampling strategies, and potentially including questions on violence that are specifically relevant to women with disabilities. In addition, training, resources, and guidance to data collection teams is needed to make data collection practices more inclusive, as well as to ensure safety for women with disabilities.

Overall, there is a need for a two-track approach – including disability in mainstream violence against women research and conducting targeted research on violence against women with disabilities.

Participants indicated the need for training of interviewers to include focus on both disability and violence against women, enabling interviewers to feel comfortable asking sensitive questions and addressing stigma against both disability and violence experiences. Identifying and training field researchers with skills to interview on these challenging topics is difficult in many contexts. Interviewers need to be trained on basic skills in interacting with women with disabilities, and researchers need to ensure that the team of interviewers have the skills and tools to accommodate different modes of interviewing, to enable greater inclusion of a range of participant abilities.

Participants noted that while the focus of the Expert Meeting was on large-scale, nationally representative prevalence surveys, the data and evidence garnered from these surveys will not fit all purposes. Data from large-scale surveys are needed for tracking progress nationally and globally, including on the Sustainable Development Goals and supporting countries’ data needs, however, for monitoring and evaluation and programmatic needs, other forms of measurement and data are needed.

Participants emphasized that ethics and safety standards and procedures in research on violence against women with disabilities is central to discussions of data production. In addition to the usual ethics and safety recommendations for research on violence against women, additional aspects for consideration include that women with disabilities may be dependent on, or face greater surveillance from, family members or carers, and therefore have additional barriers to reporting on experiences of violence. For example, greater surveillance
may result in part due to misconceptions surrounding autonomy of persons with disabilities, including their capacity to make informed decisions. As perpetrators of violence against persons with disabilities may themselves be family members and/or carers, where adequate safety measures are not in place (particularly in door-to-door sampling), this may place participants’ safety at risk.

High-quality, ethical data collection on violence against women with disabilities has additional costs that need to be budgeted from the outset.

2. Existing approaches to methodology and measurement of violence against women with disabilities:

Dr Sarah Meyer, consultant to WHO/HRP, presented on results from a scoping review on measurement of violence against women and disability. The review included quantitative peer-reviewed and grey literature, examining violence against women with disabilities, and mapped definitions, measures, and methodologies in the quantitative literature on violence against women with disabilities. Results indicated that most studies either focused on one type of disability or assessed several different types of disability as one category for the purposes of analysis. This represents a significant gap, as forms and perpetrators of violence and risk and protective factors for violence may vary based on different types of disability. Women with disabilities may be excluded from research for reasons pertaining to methodology – e.g., telephone surveys may exclude women with hearing disabilities, or for reasons pertaining to research ethics procedures – for example, the belief that women with cognitive disabilities may be unable to give informed consent. However, few studies took specific measures to ensure inclusion of women with disabilities by developing or adapting specific data collection methods or ethics protocols. In addition, few included studies took measures to adapt ethics procedures, such as delivery or design of informed consent processes, to ensure that women with disabilities for whom these procedures could form a barrier to participation in research can be included.

Dr Kristen Diemer from the University of Melbourne, reported on an Asia Pacific regional consultation on measuring prevalence of violence against women with disabilities conducted as part of the kNOwVAWdata initiative, funded by UNFPA and DFAT. The consultation aimed to identify key data needs and objectives for measuring violence against women with disabilities, clarify the objectives of a survey to measure violence against women with disabilities, and explore existing disability measures. The consultation emphasized that women with disabilities are currently excluded from violence against women research, for several reasons. First, that household sampling strategies often exclude women living in institutions, supported accommodation and group housing. Second, that interviewing women with communication, sensory and/or cognitive impairments may require assistance or interpretation, which may undermine safety and confidentiality. Third, questions about specific acts of violence which women with disabilities are at greater risk of are often not included in violence surveys, i.e., violence specific to different forms of disability – for example, withholding of medicines and/or assistive devices, or ignoring or refusing requests for assistance with daily activities, such as bathing or eating.

Participants in the consultation agreed that measuring disability in the context of surveys that are primarily for another purpose (i.e., violence against women surveys) can be different than detailed measurement of the prevalence of disability in a population. In the context of dedicated violence against women surveys, the disability questions may need to be limited in number to be feasibly included, while also producing consistent, comparable, and reproducible data.

Participants in the consultation agreed that the Washington Group Short Set questions will not identify everyone with disability, and that it is a limited measure – what is actually being measured are functional limitations, not disability. However, there was agreement that the WGSS questions are feasible to implement and produce consistent and internationally comparable,


if limited, data. The consultation recommended that where the WGSS is used, limitations should be acknowledged, and a ‘catch-all’ question asking about any form of disability can be added, to supplement aspects of disability that the WGSS questions miss. It was also recommended that more methodological research be done to explore other measures.

Overall, a shift in perspective from ‘hard to reach’ to ‘easy to ignore’ is needed, along with concrete actions to improve measurement of violence against women with disabilities, such as inclusion of women with disabilities in the research team from the stage of initial consultation. This needs to be budgeted for to be safe, effective, and meaningful.

Participants in the Expert Meeting noted that the perspective of inclusion needs to start from an understanding of the barriers for participation – in all phases of research – for women with disabilities. Discussion included the challenges of disaggregation for violence and disability in a large survey like DHS, where the sample size for violence against women with disabilities may be 200 women. The question of what the purpose of a specific survey is, and what is possible within a specific survey, was discussed. Researchers can consider what is the best data we can get in a disability-focused survey and what is the best data we can get in a violence-focused survey, and clearly communicate to donors, policymakers and other data users what is possible to measure within a single survey as well as the limitations of the data.

There is a need for dedicated surveys on violence against women with disabilities, with appropriate sampling frames and approaches. Such work will provide a better and more nuanced understanding of the prevalence of different forms of violence against women with different types of disability. Currently, small sample sizes of women with disabilities make it very difficult to disaggregate by type of disability.

Dr Nayreen Daruwalla, from the Society for Nutrition, Education and Health Action [SNEHA] in Mumbai, India, presented on findings from research on the associations between disability and violence against women in the context of a randomized controlled trial of community interventions for primary and secondary prevention of violence against women and girls in Mumbai informal settlements. Results showed very low reporting of self-care and communication disabilities, according to the WGSS questions. In another study, using convenience sampling, it was challenging to include women with disabilities apart from blindness. Many of the challenges of data collection on violence against women and disability could be addressed using mitigation strategies. For example, disability classification was difficult and confusing for field investigators, however, training on understanding disability addressed this challenge. In addition, finding a safe space for women to be interviewed could be challenging where women had mobility issues, and the mitigation strategy required careful planning to be able to visit the woman when she was able to talk at home. Challenges of collecting data from women with cognitive disabilities were addressed by developing a visual flip chart to elicit responses.

Group discussions of what modifications to existing survey methodologies may be needed elicited the following considerations:

- Use multi-methods to triangulate findings with other methods, especially qualitative methods, which can also be used to generate and agree on suitable items for addition to survey modules
- Include women with disabilities in all aspects of survey design and implementation
- Flexible timeline to accommodate inclusion with realistic funding
- Daily debriefing, counselling and support for VAW researchers to enable researchers to promote disability sensitivity
- Training – dedicated modules on disability, re-training throughout the survey period
- Create safe spaces for survey – invest in creative ideas on how to create safe spaces, for example ways of intervening with the caregiver/family (in a way that will not raise suspicion regarding potential violence disclosure) to allow conversation with the woman alone in a private setting
- Creative ways to design a process for informed consent with women who are cognitively impaired (in line with principles of informed decision
making, i.e. begin from assumption that women with cognitive disabilities can undergo informed decision making processes, as outlined within the Convention on the Rights of Persons with Disability)³

- Appropriate remuneration for participation in the research, including for peer researchers
- Appropriate sampling to allow quality data analysis
- Follow-up welfare checks with the participant 2-3 days post-survey (in line with safety considerations, and informed decision making of participants, i.e. agreement on ways to follow-up should be discussed and approved by participants ahead of time, to avoid potential safety risks).
- Include disabled persons organizations in referral lists offered to participants and consider providing capacity development to disabled persons organizations to help them better respond to gender-based violence.

Participants discussed several issues related specifically to sampling. If we are seeking to make conclusions from a population-based sample, it is important to have adequate sample size for analysis. The question of sampling and methodology more broadly is also an issue of inclusion: we know that women with disabilities exist everywhere, and if we don’t adequately include questions, accommodations, and training, we are missing them in population-based samples. Over-sampling is also a feasible approach to the concern of adequate sample size.

Participants discussed the role of population-based surveys in improving understanding of violence against women with disabilities, agreeing that the data generated in population-based surveys can shed light on magnitude and some associations. However, it cannot tell us about pathways, etiology, impacts and effectiveness of interventions. Nonetheless, population-based surveys on violence against women are useful for measuring prevalence and will continue to be conducted, so improving inclusion of women with disabilities and the issue of disability within these surveys is necessary for justice, inclusion, and representation. It will also contribute to the understanding of violence against women and disability.

3. Washington Group Short Set questions and other measurement tools:

Dr Kristen Diemer presented results from national violence prevalence studies that have utilized Washington Group Short Set questions. Mongolia (2017), Bhutan (2017), Viet Nam (2018) and Sri Lanka (2019) all utilized them as part of a dedicated VAW survey, and Kiribati (2018), Samoa (2019), Tonga (2019) and Tuvalu (2019) included them as part of a MICS survey with the DHS domestic violence module. Results from Mongolia indicated that women who reported ‘a lot of difficulty or cannot do’ to at least one of the functional areas were more likely to report various forms of intimate partner violence (IPV). In Bhutan, there were 11 respondents with disability (5.8% of ever partnered women), and women who reported disability reported twice the prevalence rate of lifetime physical IPV and lifetime sexual IPV than women without disability. Lifetime psychological IPV and controlling behaviors, as well as current psychological IPV, physical IPV, sexual IPV and controlling behaviors were all higher for women reporting disability. In Viet Nam, findings indicating elevated risk of IPV amongst women reporting disability according to the WGSS questions prompted recommendations to review, revise, and supplement current policies and laws to ensure full coverage and accessibility to support services for the most vulnerable groups of women, including women with disabilities, and to allocate additional resources to understand barriers to help-seeking among all women, especially those in high risk groups such as migrants, ethnic minorities, youth and women with disabilities. The Tonga survey indicated challenges with analysing disability and IPV given small sample sizes: 333 women reported IPV, 42 women reported functional disability, and 18 women reported IPV experience and disability. Results in these surveys indicated that the WGSS questions can provide a consistent and comparable measure of disability. However, the WGSS questions do not allow an in depth understanding of the different types of disability and exclude some important types of disability that may be highly associated with VAW, such as chronic pain. The questions require careful translation, cognitive testing among women with disabilities, and dedicated training on the module and on disability-sensitivity to country teams. These surveys indicate that inclusion of questions that enable disaggregation of violence prevalence for disability is possible, but that using WGSS questions in population-based surveys poses challenges of small sample sizes.

³  CRPD/C/GC/1, para. 42
Moreover, the WGSS questions define some women with important limitations on functioning as non-disabled, as they only include certain types of disability.

Dr Kristin Dunkle, from the South Africa Medical Research Council in Pretoria, South Africa, presented longitudinal data using the WGSS questions, as part of a series of intervention studies implemented under What Works to prevent VAWG, which shed light on some limitations of the WGSS questions. Existing cross-sectional data cannot shed light on whether disability increases risk and severity of IPV over time, and whether IPV increases risk and severity of disability over time. A hypothesized cycle of violence and disability is that increased severity of existing physical, mental or psychiatric disabilities or newly arising physical, mental or psychiatric disabilities can result in i) increased physical, emotional and economic dependency on (potential) perpetrators, ii) increased stigma and discrimination and iii) increased difficulty leaving or seeking help for abuse. These factors can in turn result in increased risk of initiation of any form of violence against women or increase in duration or severity of violence. Findings indicated that the category of disability is variable across time, and up to 50% of people moved from one disability category to another over the course of some of the studies. Results from intervention data show that in Rwanda and South Africa, increasingly severe disability level at baseline led to increased physical, sexual, economic and emotional IPV, whereas in Afghanistan, only disability at baseline was associated with IPV at endline. No study showed a clear association between IPV experiences and disability at endline, indicating that the WGSS questions may not be measuring the types and extent of disability most likely to change in programme time frames. The timeframes and mechanisms through which IPV leads to increased disability requires further investigation and is not adequately captured by the WGSS questions. The WGSS questions were not designed for programmatic use or for detecting prevalence within non-census surveys and are inadequate for correctly identifying and tracking women with disabilities enrolled in IPV prevention programmes.

Dr Kaloyan Kamenov, Technical Officer with the Disability Programme at WHO, presented on WHO tools for collection and disaggregation of disability data. WHO tools are based on the International Classification of Functioning, Disability and Health [ICF], which defines disability as the outcome of the interaction between health conditions or impairments and environmental factors. The scoping review found that over 50% of studies utilized measures that do not match this definition of disability, as they only focus on the health condition. The WHO-DAS 2.0 is a generic assessment instrument for measuring disability in clinical practice and at a population level. It is useful for brief assessments of overall functioning, and at 12 items, is short and easy to administer. It has excellent psychometric properties and cultural comparability and is directly linked to the conceptual basis of disability in the ICF; however, it contains questions concerning activities and participation domains but does not capture pain and does not provide information on environmental factors. The Functioning and Disability Disaggregation [FDD11] is based entirely on the Model Disability Survey capacity module and captures functioning across body functions and activities and participation domains. It is brief and can be administered quickly, has excellent psychometric properties and provides prevalence of disability and allows for disaggregation by severity level (no disability, mild, moderate and severe) [7]. The FDD11 does not provide information on environmental factors. Efforts to measure not just prevalence but also disaggregate key indicators (i.e., help-seeking, health service utilization) are important. In addition, health care providers’ assessment and facility-level data are fundamental to improving data on disability.

Participants discussed the shortcomings of the WGSS questions. Developing a module of violence against women questions for use in disability surveys is feasible, and the greater challenge is which disability measure to include in violence-focused surveys. Given the WGSS questions have been utilised in many national violence prevalence surveys and the What Works studies, researchers must confront the challenges and shortcomings of the WGSS, while weighing the value of comparability with existing datasets.

Participants emphasized that the degree of under-reporting of disability with the WGSS questions indicates that the prevalence identified is likely to be the tip of the iceberg in terms of actual disability prevalence. The WGSS questions were designed for census use, and do not capture many kinds and dimensions of disability; for example, disability is a time-varying construct, and this is not captured by the WGSS questions. WGSS also omits chronic pain, disabling illness, and most disabling psychiatric conditions, all of which are likely to be related to experiences of violence.
4. Inclusion of women with disabilities in research:

Dr Jane Ndungu from the Medical Research Council in Pretoria, South Africa, presented on inclusion of women with disabilities in research. Inclusion of women with disabilities in research is about creating a carefully thought-out environment, where women with disabilities can participate in activities of importance to them with dignity. This involves trust, acknowledgement of lived experiences of women living with disabilities, and utilizing data collected as promised/intended. Inclusion involves adapting policies, structures, and research methods. Policies including funding policies that are flexible and are designed to accommodate active inclusion of women with disabilities from the outset. In terms of structures, inclusion cannot be an afterthought – it will not work, and it will undermine the credibility of the process. Women with disabilities have sensitivity to what the problems and solutions are and can be, and inclusion from the outset can generate creative solutions. Involvement of women with disabilities from conceptualization of studies to dissemination of data ultimately cuts costs, checks the accommodation measures in place and enhances trust building with women living with disabilities included in the study as respondents. Key issues to think through when conducting research with women with disabilities include stigma associated with identifying as a person living with disability, as well as existing concerns amongst women with disabilities who are often excluded from inclusion considerations given issues around ‘how disabled do you need to be?’ to be defined as living with a disability. Key ethical considerations may include weighing up the need for data with the need for safety of the woman – there may be cases where researchers need to pull out given safety concerns. However, protection must be weighed with the concern of condescension; we should not assume vulnerability, and if women say they have the capacity for decisions to be involved, we should not remove more power from them.

5. Ethics and research on violence against women with disabilities:

Participants in the Expert Meeting discussed and proposed several aspects of ethical procedures and principles for research on violence against women with disabilities. Principles include:

- Active involvement and leadership from women with disabilities from point of conceptualization of research, including women with different disabilities and diverse perspectives
- ‘Nothing about us, without us’
- Adequate allocation of resources to facilitate active involvement and participation of women with disabilities
- Data production and utilization should be guided by clear prior understanding of why the data is being produced, who will utilize it and how it will be utilized
- Promote trust and safety between researchers and women with disabilities who are actively involved in conceptualization, and between researchers and research participants
- Adopt some learnings from trauma research principles
  - Recognise the impact on women with disabilities by including them in research
  - Approach each interview as though the respondent may have a disability (or trauma)
  - Ensure methods are flexible and able to be adapted to support involvement of women with disabilities
- Work closely with disabled peoples’ organizations – sometimes this means that we might need to educate them about violence against women
- Capacity building for women with disabilities to enable active involvement and engagement in conflicts in different forms of accommodation that are needed, and conversations are needed about how different, potentially conflicting needs, are addressed. Issues of power and representation may exist in partnerships with disabled persons organizations, which may need capacity-building on the issue of violence against women.

Authentic and sustainable inclusion of women with disabilities in research on violence against women requires money, creativity, scientific knowledge, time and commitment.
research (including investing in researchers with disabilities to ensure that they have the technical skills to be able to provide meaningful input)

- Work with young and new researchers to glean new ideas about research methods and creative ways to engage the community

- Inclusion should be based on the principle of ‘dignity of risk’ – allow women to decide if they want to participate in the research, don’t exclude women with specific disabilities from the outset based on researchers’ assumptions of their (women’s) risk

- Capacity to consent – all respondents can be asked 4-5 questions to assess comprehension of the informed consent process; this should not be limited to participants thought to have a disability

- Referrals to accessible services

  - GBV service providers may need training on disability awareness, sensitivity and accessibility

  - Accessibility will mean different things in different places, i.e. online access, accessibility for communications (sign language), information (accessible formats), transportation, accessibility of assistance devices, accommodations for accompaniment

- Cautious consideration of emergency protocols considering the risk to respondents if help is brought in with or without her consent – support services may not be disability or violence aware and can cause more harm.

Recommendations – measuring violence against women and disability

Evidence:

1. Surveys on the prevalence of violence against women need to include measures of disability, recognizing that this will provide prevalence on violence against women with disabilities which reflects only the tip of the iceberg and are likely underestimates. Where selection of measures is limited by budgetary and logistic constraints, research teams need to recognize and clearly communicate the limitations of the selected measure, especially where it is known to underestimate the true prevalence of disability (eg the Washington Group Short Set [WGSS] questions).

2. These surveys can also capture impact and consequences of violence against women with disabilities. However, these surveys tend to have small numbers of women with disabilities and even smaller numbers reporting violence. Where population-based surveys include small numbers of women with disabilities reporting violence, acknowledge the limit on possibilities for further disaggregation (i.e. by age, socio-economic status), or consider targeted oversample or shifts in sampling frames to include more women with disabilities.

3. Measures of disability should be as inclusive as possible (both in forms of disability and forms of disability specific violence), taking into the account the need for short measures due to the constraint of overall survey length

4. Population-based survey data need to be complemented by qualitative research that can offer a better context to disclose sensitive information and therefore provide more nuanced information on the interplay between different types of disability and different forms of violence against women and can help understand bidirectionality, causal pathways and dynamics of perpetration as well as prevalence.

5. Existing evidence can be supplemented by improved understanding of specific forms of violence experienced by women with disabilities, and a short module focusing on these forms of violence can be developed and piloted. This module should be developed based on a workshop to generate consensus on items to measure violence that capture disability-specific forms of violence (i.e. denial of medical, personal assistance and other critical support) that can be used within existing surveys. This workshop should include women who have experience of diverse forms of disability and from diverse contexts.

6. Need for more longitudinal research to track changes in prevalence of violence and disability over time, and assess reciprocal causality between disability and violence against women
7. Need for intervention research, including randomized controlled trials, to assess what works to prevent violence against women with disabilities.

8. Need for policy-research, to identify if and how specific policies affect women with disabilities and their experiences of violence.

**Inclusion of women with disabilities in violence against women research:**

1. Inclusion of women with disabilities in research needs to occur from the outset, with women experiencing a range of visible and invisible disabilities. This entails that inclusion of women with disabilities needs to be an integral part of all research initiations from the initial planning stage onwards, and not as an afterthought. This could include peer researchers.

2. Partnerships with disabled person’s organizations (and specifically, women’s wings of or women-focused disability organizations) need to be established from the outset, with attention to pre-existing power imbalances which may limit access to perspectives of women with disabilities. Reciprocal capacity development between experts on violence against women and experts on disability may be required.

3. Establish structures for inclusion of women with disabilities at the project level for prioritizing research questions, informing study design, design of study instruments and data collection procedures, member-checking, all aspects of data dissemination and knowledge exchange back to the community, and evaluation of the research process.

4. Inclusion of women with disabilities in research as co-owners and/or as participants requires adequate and discretionary funding to provide necessary accommodations to facilitate full participation. This may include accessible transportation, accommodations, accompaniment, interpreters, etc.

5. Ensure survey materials are available in a range of accessible formats which are disability accommodating and inclusive (e.g., easy read formats such as large print, braille, technological assisted tools as required – electronic materials for be optimized for accessibility in using screen readers for example)

6. Inclusion of women with disabilities in research requires flexibility, adaptability, and transparency as principles from the donors and researchers and involved institutions. This includes commitment to sustainable funding for follow through from design, data collection, reporting to dissemination.

7. A long-term vision for inclusion of women with disabilities in research requires capacity-building of early career researchers with technical skills to be able to engage with study design, analysis, etc. Such capacity-building requires regular technical and financial support to young researchers.

**Ethics principles**

1. Develop research ethics recommendations for research on violence and disability to include in the updated version of WHO VAW research ethics guidelines.

2. Shift the framing from ‘hard to reach’ to ‘easy to ignore’ as an ethical principle.

3. Operate from a framework of ‘dignity of risk’ and ensure that women with disabilities are enabled to make decisions about their own participation in research.

4. Assess capacity to provide true informed consent through accessible and rigorous procedures (e.g., provision of accommodations during the informed consent process, ‘Evaluation to Sign informed consent’), rather than implement blanket exclusions for women with certain disability types.

5. Study design, data collection methods and all ethics procedures should be based in principles of ensuring safety for women involved in the research and building trust between researchers and participants.

6. Provide referrals to violence-specific support services for women with disabilities participating in research on violence against women, ensuring that these services are accessible in a range of ways for a spectrum of disabilities and have the capacity (staffing and monetary wise) to absorb potential referrals, as needed. Where necessary, capacity building of disabled persons organizations on the topic of violence may be needed and can be
achieved through cross-learning between violence against women partners and disabled persons organization partners.

7. Psychological support should also be available for the research team recognizing that the interviews may be profound and triggering.

8. The safety protocol needs to be designed to be disability inclusive and in consultation with a local disability support organization that understands the safety risks associated with help-seeking and violence against women, or a local disability support organization that is provided with capacity building on the topic of violence against women.

9. Women with disabilities who are involved in the research team should be formally recognized and leave the project in an improved/advanced position, either economically or through further access to financially compensated opportunities due to skills obtained.

10. All data should be collected with a clear purpose, with guidance on how to interpret and use it, and recognition of the limitations of the data.

Data collection

1. Develop resources centrally, i.e., model consent forms for persons with cognitive impairments, training modules [different length versions], adaptations for online data collection.

2. Develop a data collection and reporting checklist for research on women with disabilities

3. Inclusion of women with disabilities within surveys and research as respondents and participants, as well as interviewers/ enumerators

4. Training and resource support for female interviewers/ enumerators to implement inclusion and accessibility guidelines, in terms of recruitment, training schedule and venue. These training modules should be required in training of all professionals and advocates who work on violence against women initiatives - not just those specifically focusing on violence against women with disabilities.

5. Training should include safe and ethical ways of managing gatekeeping at the community and household level which may exclude women with disabilities from participating in the research.

6. Include appropriate and accessible modes of data collection and dedicate adequate time and resources to ensure meaningful participation

7. Training – need explicit training about interacting with and interviewing women with different types of disabilities and support needs, sessions on stereotypes, session on disability etiquette. It may be beneficial to have some members of the field team specialized in working with respondents with disabilities.

Measures

1. Selection of disability measures should be guided by purpose of the research, feasibility and objectives of data utilization

2. For public use datasets, guidance regarding data analysis and utilization should be provided for reporting and disaggregation of disability and violence data, including whether disaggregation is recommended or possible depending on sample size.

3. Develop minimum standards for including disability in a non-disability focused survey and for including violence against women in a non-violence focused disability survey

4. Washington Group Short Set questions can be utilized for census and census-like purposes; they have limitations for programmatic or monitoring and evaluation purposes (excluding certain types of disability, underestimating levels of disability)

5. Instruments should not rely on single questions on self-reported disability status or diagnosed health conditions as the only disability measure; a supplemental catch-all question can be included where other disability measures, i.e. Washington Group Short Set, are included in the survey. For example, in the United Kingdom census, individuals are asked: “Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?”. If they answered “yes”,
a further question “Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?” was asked. The response options were: “yes, a lot”, “yes, a little” and “not at all.” Respondents who indicate “yes, a lot” can be considered people with disabilities.

6. Recommend using other tools (i.e. Functioning and Disability Disaggregation 11 Tool) to capture broader range of disability and do psychometric testing on these measures in different contexts for cultural relevance.

7. Explore different disability tools for use for programmatic and monitoring and evaluation purposes.

8. Develop a module for disability-specific forms of violence against women (to ask of all respondents) that includes different types of violence (physical, emotional, sexual, controlling behaviors); after piloting and validation, these questions could be integrated into the main question set of the WHO violence against women module.

9. Consider types of disaggregation necessary for a given study and power sample size based on estimates of proportion of population (by age group) with disability. Remember that further desegregations amongst people with disabilities (e.g., by sex, disability type, age group, gender identity) will require further increases to the sample size.

10. Consideration of sample size and numerators and denominators when conducting analyses and reporting, particularly when reporting on small cell sizes - with small numbers reporting prevalence as binary might be more accurate than reporting by type of disability.

11. Include a broader set of perpetrators of violence, including caregivers and service-providers

12. The Washington Group Short Set questions do not include mental health. Mental health can be assessed using validated and reliable mental health measures, and where these measures are included in the same survey, these data can be considered as part of reporting on disability.

13. Need a time frame for all disability questions, to capture onset of disability (how long the person has been living with it, acquired vs. from birth) and to consider how the onset of disability might impact on the time frames commonly considered in VAW surveys as well as influence the interpretation of the prevalence of women with disabilities victims of violence.

14. Further psychometric work is needed to assess the strengths and the gaps in current measures (e.g. Washington Group, and WHODAS) and if current measures:

- adequately capture the spectrum of disability and the different domains of disability (e.g. activity limitations, functioning difficulties and social participation);
- function within and across settings and time to allow for comparison of results while taking the sociocultural context into account.

15. Use of qualitative and participatory methods and mixed methods research to strengthen existing survey question sets, and the active inclusion of people with disabilities in the development of these measures.
References/Key readings


## Annex 1. Agenda

### Day 1: Thursday 10 November, 2022

<table>
<thead>
<tr>
<th>Time</th>
<th>Sessions</th>
<th>Presenters</th>
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<tbody>
<tr>
<td>9:00–9:30</td>
<td>1. Welcome and introductions&lt;br&gt;2. Meeting objectives&lt;br&gt;3. Brief background for experts meeting</td>
<td>Dr Claudia García-Moreno</td>
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<tr>
<td>9:30–10:30</td>
<td>Data and evidence on violence against women with disabilities</td>
<td>Dr Morgan Banks</td>
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<td>10:30–11:00</td>
<td>Coffee/tea break</td>
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<tr>
<td>11:00–12:15</td>
<td>Measurement of violence against women and disability – findings from a scoping review&lt;br&gt;Recommendations/conclusions from kNOwVAW data disability and violence against women meeting</td>
<td>Dr Sarah Meyer&lt;br&gt;Dr Kristen Diemer</td>
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<td>12:15–13:15</td>
<td>Lunch break</td>
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<tr>
<td>13:15–14:45</td>
<td>Washington Group questions&lt;br&gt;WHO measurement of disability</td>
<td>Dr Kristen Diemer&lt;br&gt;WHO Disability team</td>
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<td>14:45–15:15</td>
<td>Coffee/tea break</td>
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<td>15:15–17:00</td>
<td>Discussion: small group work&lt;br&gt;Recommendations for survey design and implementation</td>
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### Day 2: Friday 11 November, 2022

<table>
<thead>
<tr>
<th>Time</th>
<th>Sessions</th>
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<tr>
<td>9:00–9:15</td>
<td>Recap and review day 1</td>
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<tr>
<td>9:15–10:45</td>
<td>Inclusion of women with disabilities in research on violence against women</td>
<td>Jane Ndungu</td>
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<td>10:45–11:15</td>
<td><strong>Coffee/tea break</strong></td>
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<tr>
<td>11:15–12:15</td>
<td>Regional perspectives on measurement of violence against women with disabilities</td>
<td>Dr Nayreen Daruwalla</td>
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<td>Dr Kristen Dunkle</td>
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<td>12:15–13:15</td>
<td><strong>Lunch break</strong></td>
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<tr>
<td>13:15–14:30</td>
<td>Discussion and group work – developing recommendations on measurement and evidence-generation on violence against women with disabilities</td>
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<td>14:30–15:00</td>
<td><strong>Coffee/tea break</strong></td>
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<tr>
<td>15:00–16:30</td>
<td>Discussion – recommendations and next steps</td>
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<tr>
<td>16:30–17:00</td>
<td>Summary and conclusion</td>
<td>Dr Claudia García-Moreno</td>
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Annex 2. List of Participants

Morgon Banks  
London School of Hygiene and Tropical Medicine  
London, United Kingdom of Great Britain and Ireland

Nayreen Daruwalla  
Society for Nutrition, Education and Health Action [SNEHA]  
Mumbai, India

Kristin Diemer  
Department of Social Work, School of Health Sciences  
The University of Melbourne  
Melbourne, Australia

Kristin Dunkle  
South African Medical Research Council  
Cape Town, South Africa

Violet Kalayi Wawire  
Kenyatta University  
Nairobi, Kenya

Malebogo Molefhe  
Gender-based violence and disability activist  
Botswana

Elizabeth McGuinness  
Independent Consultant  
Geneva, Switzerland

Jane Ndungu  
South African Medical Research Council  
Cape Town, South Africa

Mahesh Puri  
Centre for Research on Environmental Health and Population Activities  
Kathmandu, Nepal

Jean-Francois Trani  
Washington University in St Louis  
St Louis, United States of America

Laisa Vereti  
Pacific Disability Forum  
Suva, Fiji

Representatives of other UN Organizations including the United Nations Inter-Agency Working Group on Violence Against Women Estimation and Data

Raphaëlle Rafin  
United Nations Entity for Gender Equality and the Empowerment of Women (UN Women)

Margaret Mbogoni  
Demographic and Social Statistics Branch  
Statistics Division, United Nations Department of Economic and Social Affairs

WHO Secretariat

Claudia García-Moreno  
UNDP-UNFPA-UNICEF-WHO-World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP), Department of Sexual and Reproductive Health and Research (SRH)

LynnMarie Sardinha  
UNDP-UNFPA-UNICEF-WHO-World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP), Department of Sexual and Reproductive Health and Research (SRH)

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