



# Measuring the Prevalence of Violence against Women with Disabilities

Summary report from a kNOwVAWdata initiative consultation  
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## Introduction

The Australian Department of Foreign Affairs and Trade (DFAT) and UNFPA are partnering in an initiative to support and strengthen sustainable regional and national capacities to measure violence against women in the Asia-Pacific region. As part of this regional initiative, kNOwVAWdata, DFAT and UNFPA, together with the University of Melbourne, brought together national, regional and global experts to discuss what approaches should be taken to ensure that women with disabilities are better represented in national prevalence studies on violence against women. Participants attending the one day meeting included representatives from Disabled People's Organisations, government agencies, non-government organisations and academia (see Appendix 1 for full participant list, noting that some global experts participated via videoconference during the meeting).

The meeting was held in a roundtable format and heard from women with disabilities about their perspectives on violence research; considered researchers' experience investigating violence against women with disabilities in Asia and the Pacific; discussed the ethical and safety issues associated with research on violence against women with disabilities; and considered how best to increase understanding of the experience of violence against women with disabilities in the region, including through national violence prevalence studies.

This short report summarises discussions that were held on the day. It includes a brief overview of the current situation and suggested ways forward for researchers, the kNOwVAWdata initiative and other regional and global initiatives to measure prevalence of violence against women with disabilities, and for relevant regional and national institutions (including statistics offices, women's machineries and the disability sector).

### **Opening and Introduction:**

**Amy Haddad (DFAT) Assistant Secretary, Principal Gender Specialist**

#### **Key points**

The Australian Government is committed to:

- 1. Working through the kNOwVAW partnership (UNFPA, University of Melbourne and Australian National Research Organisation for Women's Safety (ANROWS)) to make sure violence against women with disabilities is counted**

### **Introduction of the kNOwVAW data program and the rationale for the meeting:**

**Helen McDermott (DFAT), Assistant Director, Gender, Violence and Security section**

#### **Key points**

The Department of Foreign Affairs and Trade has committed to:

- 2. Placing a focus on women with disabilities across the program, particularly given there are big data gaps in relation to violence against women with disabilities**

## What is known about violence against women with disabilities and the evidence gaps, with a focus on Asia and the Pacific

Some of the key literature on violence against women with disabilities was presented to the meeting and is summarised below. More detail about these studies can be found in Appendix 2.

Analysis of data generated through the 2012 *Personal Safety Survey* in Australia found that people with disabilities were significantly more likely to experience all types of violence, than people without disabilities. Women with disabilities are more likely to experience sexual and intimate partner violence than women without disabilities, and men with or without disabilities (Krnjacki et al. 2016).

In 2012, a global systematic review and meta-analysis of observational studies on violence against adults with disabilities was published in the *Lancet* (Hughes et al. 2012). This review found that adults with disabilities are at higher risk of violence than adults without disabilities, and that people with psychosocial disabilities could be particularly vulnerable. The authors however noted that there is a pressing need for further research in this area, with high quality studies from low- and middle-income countries especially scarce.

While there is limited evidence from low- and middle-income countries, DFAT (and previously AusAID), have supported a number of studies relevant to understanding violence against women in Asia and the Pacific. The mixed-methods *Triple Jeopardy* study in Cambodia found that women with disabilities are just as likely to experience intimate partner violence as women without disabilities. This study also found that women with disabilities were up to 4.2 times more likely to experience controlling behaviour from partners, and were significantly more likely to experience violence from other family members (Astbury et al. 2014).

The *W-DARE* study in the Philippines found that women with disabilities commonly reported violence, with women with particular types of impairment reporting both severe violence and major barriers to services. This was particularly the case for women with psychosocial disabilities, women with intellectual disabilities, and women who were deaf or hard of hearing. Women with disabilities reported violence from a wide range of perpetrators (Vaughan et al. 2016).

The *A Deeper Silence* report was based on interviews with women in Kiribati, the Solomon Islands and Tonga and described the different forms of violence that women with disabilities are subject to, including the withholding of medication and assistance, denial of food or water, and forced sterilisation and medical treatment. The report noted that the consequences of violence against women with disabilities can be severe (Spratt 2013).

Importantly, the recent *Nabilan Baseline Study* in Timor-Leste that adapted the WHO Multi-country Study methodology to undertake a study to measure the prevalence of violence against women aged 15 to 49 years, included five of the six Washington Group Short Set of Questions on Disability. The Nabilan study found that women who reported intimate partner violence were significantly more (2.5 times) likely to be at risk of disability<sup>1</sup>, that is women who reported a lot of difficulty with seeing, hearing, remembering, concentrating or

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<sup>1</sup> As will be discussed below, the Washington Group Short Set of Questions on Disability (WGSS) measures the functional limitation associated with impairment, rather than disability. As it is not impairment, per se, that causes disability, but rather the interaction between impairment and barriers to participation, the WGSS should be seen as identifying people 'at risk of experiencing disability' rather than people 'with disability'. However, the WGSS is commonly used as a proxy measure of the prevalence of disability at a population level.

communicating, or not being able to do these functions at all (The Asia Foundation 2016). This study represents one of the first examples of a national study of the prevalence of violence against women where it is possible to look specifically at the experience of women at risk of disability, and was presented at the meeting by Sophia Cason from The Asia Foundation.

Dr Henriette Jansen (UNFPA) presented preliminary analysis from a very recent study to measure prevalence of violence against women in Mongolia, where (an adapted version of) the Washington Group Short Set of Questions on Disability were also incorporated into the WHO Multi-country Study questionnaire. This analysis showed that women reporting 'a lot of difficulty' with functioning or not being able to perform a functional activity at all, were more likely to report having experienced violence than women without functional limitations.<sup>2</sup>

### What evidence is there about violence against women with disabilities?

#### Key points

3. Evidence is limited, with very few examples of population-based studies of prevalence of violence against women with disabilities
4. What evidence there is from Asia and the Pacific suggests that women with disabilities:
  - may be more likely to experience violence than women without disabilities;
  - experience violence from a wide range of perpetrators, including but not limited to intimate partners; and
  - that women with some types of impairment may experience particularly elevated risk.

## Supporting progress toward the Sustainable Development Goals through the kNOwVAWdata initiative

The kNOwVAWdata initiative supports countries in Asia and the Pacific to measure prevalence of violence against women and girls and to report on the fifth Sustainable Development Goal (SDG), **To achieve gender equality and empower all women and girls**, and specifically 5.2.

**Target 5.2: Eliminate all forms of violence against women and girls in the public and private spheres including trafficking and sexual and other types of exploitation.**

Indicators are:

- 5.2.1 Intimate Partner Violence: Proportion of ever-partnered women and 15 years and older subjected to physical, sexual or psychological violence by a current or former intimate partner, in the last 12 months, by form of violence and by age group
- 5.2.2 Sexual Violence: Proportion of women and girls aged 15 years and older subjected to sexual violence by persons other than an intimate partner, in the last 12 months, by form of violence and by age.

There was considerable discussion during the meeting about the difficulty of measuring progress towards the elimination of *all* forms of violence against *all* women and girls in both the public and private sphere. It was acknowledged by the meeting that the two indicators for target 5.2 of the SDGs measure two important forms of violence against women, but do not capture all the forms of violence that women experience and, in particular, do not

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<sup>2</sup> [\*The report of the Mongolia national violence against women study will be released in early 2018.\*](#)

capture a large proportion of the violence that is experienced by women and girls with disabilities including violence in institutional and closed settings. It is important that these indicators do not distort and narrow understanding of women's experiences of violence over a lifetime, and **should not be used as a proxy for all violence against all women**.

Women with disabilities present at the meeting emphasised that a focus on intimate partner and sexual violence only is a legacy of feminist activism on violence against women, which has historically neglected the experience of women with disabilities. The voices of women with disabilities have generally been ignored, leading to the inaccurate assumption that the violence experiences of women with disabilities are the same as those of women without disabilities.

It was acknowledged that at this time, however, there are recognised and agreed tools for measuring intimate partner and sexual violence, and that far more work needs to be done to establish appropriate, effective, agreed and internationally comparable methods for measuring many of the structural, institutional and interpersonal forms of violence women with disabilities experience on a daily basis. While it was recognised that the focus of the kNOwVAWdata initiative is to support countries to accurately measure the prevalence of intimate partner and sexual violence, those present at the meeting encouraged the partnership to also contribute to efforts to develop more inclusive categories of violence.

While there are limitations associated with the indicators for target 5.2 of the SDGs, they are important. In monitoring progress towards the elimination of intimate partner and sexual violence, it is vital that countries are able to use prevalence data to ensure that efforts to prevent these forms of violence 'leaves no one behind'. This means that prevalence studies need to incorporate questions that will enable disaggregation of data by disability.

## Limitations of agreed tools

The WHO Multi-Country Study on Women's Health and Domestic Violence methodology and the Domestic Violence Module of the Demographic and Health Survey are two of the most widely used tools for measuring prevalence of intimate partner and sexual violence against women, producing internationally comparable data. National estimates of the prevalence of violence against women in Asia and the Pacific have largely been based on data collected using one, or both, of these tools. The training curriculum that will be designed for the kNOwVAWdata initiative is also based on these approaches to measuring the prevalence of intimate partner and sexual violence against women. While these tools are internationally validated and widely used to collect high-quality data, there are notable limitations in relation to measuring the prevalence of violence against women and girls with disabilities. For example:

- Sampling strategies for violence against women surveys are primarily designed to select households (and within these, one woman per household) or occasionally to directly select women in the general population, usually excluding women living in institutions, supported accommodation and group housing, or closed settings (including hospitals and prisons)
- Eligibility criteria for selecting women within households has usually enabled the exclusion of women who are 'incapacitated', which increases the likelihood of potential female household members with communication, cognitive and other impairments being excluded
- Survey tools measure, in particular, 'domestic' violence among ever-partnered women and – less in-depth – sexual and often also physical violence by persons other than intimate partners. They have not been designed to capture other forms of violence perpetrated in domestic and institutional settings by persons other than intimate partners, that are specifically relevant to women with disabilities (such as economic, physical or

sexual forms violence and controlling behaviours perpetrated by other family members, care workers, and other residents in group homes)

- Prevalence of disability is known to increase with age, and so monitoring prevalence of violence against women with disabilities requires collecting data generated by interviews with older women. However in most Demographic and Health Surveys, and some dedicated violence against women surveys, women over 49 years of age are not included. In general, dedicated surveys on violence against women have upper age limits (set at a variety of levels)
- Data on violence (especially types of violence perpetrated by others than intimate partners) often do not include the severity, duration or frequency of violence, which may be especially important in understanding the experience of women with disabilities who face additional and particular barriers to supports and services, and may experience violence over long periods of time (with qualitative evidence from the projects identified above suggesting that some women with disabilities may experience violence throughout their lives)
- Many forms of violence experienced by women with disabilities – such as institutional violence, forced sterilisation, involuntary restraint, over and/or under medication, and removal of assistive devices – are not captured
- The most severe cases of violence will also not be counted (including death, imprisonment, and institutionalisation), which may particularly exclude the experiences of women with disabilities
- Women with severe and profound functional limitation are typically excluded from surveys
- Interviewing women with communication, sensory and/or cognitive impairments may not be possible without assistance or interpretation, which may undermine safety and confidentiality. This is particularly the case for women who primarily communicate with the assistance of family members, who may also be perpetrators of violence. To date this ethical and safety issue has not been addressed in the guidelines most widely used by researchers seeking to produce statistics on violence against women
- The cross-sectional nature of household surveys means it is not possible to show causality or the direction of any association between violence against women and disability (i.e. which came first – disability followed by violence, disability because of violence, or disability coincidental and unrelated to the violence).

## Producing violence prevalence data that can be disaggregated by disability

The *Convention on the Rights of Persons with Disabilities* emphasises that disability results when the interaction between a person's impairment and their (physical and interpersonal) environment produces restrictions in participation. The complexity and evolving nature of the concept presents particular challenges for the measurement of disability. Different tools that have been developed to measure prevalence of disability in a population, including the Washington Group sets of questions on disability and the WHO Model Disability Survey, are underpinned by different philosophical approaches to disability and its measurement.

The Washington Group sets of questions on disability are based on the *International Classification of Functioning, Disability and Health (ICF)*, a framework long endorsed by WHO member states. The Short Set of questions (see text box on page following) is designed to identify the majority of people in a population who are at greater risk than the general population of experiencing restrictions to their participation in society. They do this by identifying people who report difficulty with the functions of seeing, hearing, walking, cognition, communication and self-care (i.e. functional limitation). The recently developed DHS Disability Module is based on the Washington Group Short Set of questions. The

longer WHO Model Disability Survey is designed to provide information about how people conduct their lives and the difficulties they encounter, regardless of underlying health condition or impairment (i.e. focuses on the barriers that contribute to disability). Providing detailed information about the barriers people experience can inform efforts to ensure that 'no one is left behind' in the SDG agenda.

### **The Washington Group Short Set of Questions on Disability**

[Preamble: The next set of questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM]

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

The response categories for all six questions are:

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

Strategies for measuring disability in the context of surveys that are primarily for another purpose (such as a survey for measuring the prevalence of violence against women) have some different considerations than strategies for measuring the prevalence of disability in a population. When used in the context of a survey that is primarily for another purpose, questions to measure disability need to be sufficiently brief to be feasibly included, while still producing consistent, reproducible and internationally comparable data.

Dr Jennifer Madans (Founding member of the Washington Group on Disability Statistics and Associate Director for Science, US National Center for Health Statistics) presented to the meeting via videoconference, and outlined the state of current global debate about how to best produce violence prevalence data that can be disaggregated by disability. She noted that capturing disability in surveys on violence against women is a relatively new area and that there is as yet no consensus on optimal ways of measuring disability in this context.

There is recognition that the main tools for measuring the prevalence of intimate partner and sexual violence against women in a population (the WHO Multi-Country Study methodology and the DHS Domestic Violence module) are already quite long instruments, and that therefore any additional questions asked in order to capture disability need to be limited in number. While there is a brief version of the Model Disability Survey, it is still quite long in comparison to the Washington Group Short Set of questions, suggesting that the latter is more feasible to use in this context.

While Dr Madans, and participants at the meeting, acknowledged that not everyone at greater risk of disability will be picked up by the Washington Group Short Set of questions,



there was agreement that the inclusion of these questions would be feasible in a study primarily designed to measure the prevalence of intimate partner and sexual violence; would produce consistent and internationally comparable data; and would enable disaggregation of data to assess differences between women at greater risk of disability and women without disabilities, in relation to their reporting of violence.

Recent experience in Timor-Leste and Mongolia suggests that inclusion of questions designed to enable disaggregation of violence prevalence by 'disability' is possible. However the experience of this process shared at the meeting highlighted that:

- careful translation of Washington Group Short Set questions and response categories, and extensive cognitive testing (including with women with disabilities), is essential;
- the inclusion of these questions can substantially increase the time taken for completion of each questionnaire; and
- specific support needs to be provided to country teams, including in relation to analysis and presentation of findings disaggregated by disability.

Dr Madans confirmed that the Washington Group on Disability Statistics provide guidelines for cognitive testing, implementation, analysis, and a range of other resources and technical support, on their website: <http://www.washingtongroup-disability.com>

Participants at the meeting noted that, given what is known about the potentially elevated levels of violence experienced by women with a psychosocial disability (also referred to as mental illness), it may be desirable for future studies to explore inclusion of some questions from the Washington Group Extended Set that more specifically capture affect (anxiety and depression). However, discussion at the meeting also highlighted that in population surveys, the extent to which data can be disaggregated by the different types of functional limitation recorded (difficulty seeing, difficulty hearing etc.) is quite limited, given the number of respondents in each category may be too small to make statistically valid conclusions. This is particularly the case in studies primarily aimed to measure something else, such as the prevalence of intimate partner and sexual violence against women, where the study will be powered to detect violence rather than disability.

## Who should be involved in conducting the research?

Workshop participants expressed a strong preference for research teams to include members with the lived experience of disability and of violence. Achieving this may require the provision of training and support to women with disabilities to enable them to be co-researchers and/or enumerators, and to be involved throughout the research process including in the analysis of data and dissemination of findings. Researchers working in the region have described the benefits of including people with disabilities as co-researchers (Madden et al. 2016; Devine et al. 2017), though it is important to note that this participation must be adequately budgeted for to be effective, safe and meaningful.

It was also deemed important to involve a multi-disciplinary team of academics, practitioners, policy makers and persons with the lived experience working together as a reference group to support the inclusion of women with disabilities in violence research. It was also recognised, however, that in many countries in Asia and the Pacific, there may be a limited number of women with disabilities with the skills and experience to make a meaningful contribution to such a reference group, with research teams often repeatedly drawing on the same people and Disabled People's Organisations, contributing to 'burn out' and research fatigue. To minimise this risk, it is important that countries support national Disabled People's Organisations with both resources and capacity building.

## Moving forward – suggestions for the kNOwVAW initiative

There are very real challenges in the collection of data on women's experiences of violence, and on disability, and there are limitations to tools used to measure both of these aspects of women's lives. However, the tools we do have allow us to collect valuable and policy-relevant data. It is important that this data collection continues, while we also continue to learn and make advances in the refinement of measurement tools and approaches to understanding the breadth of women's experiences in relation to both violence and disability.

### Approaches to the measurement of disability

At this point in time the Washington Group Short Set of questions is the most feasible tool to incorporate into a dedicated survey on intimate partner and sexual violence against women. It is also important to note that the 2014 United Nations Expert Group Meeting on Disability Data and Statistics, Monitoring and Evaluation recommended the use of the Washington Group Short Set for monitoring the SDGs (and therefore in disaggregating data collected in relation to SDG indicators).

In relation to the Washington Group Short Set of questions, the Washington Group on Disability Statistics recommend:

1. That the Short Set is best used as it has been designed. They recommend not adapting or altering either the questions or the response options. Changes will lead to inaccurate collection and reporting of data, and render results incomparable with those obtained in other studies (either within the same country or internationally)
2. Careful translation and extensive cognitive testing, including with people with disabilities, and that this should be adequately resourced. Guidelines for cognitive testing (and translations for many languages) are available on the Washington Group website
3. Not introducing screening questions before an item (e.g. do you wear glasses?). Introducing screening questions generally results in under-reporting
4. Excluding items that are not relevant to the majority of the population. For example, if stairs are non-existent in a given country, then remove that question rather than modifying it or asking it and obtaining data that is not useful
5. That if additional questions are added to the Short Set (for example, the additional items on affect and upper limb functioning that constitute the Short Set-Enhanced), that this is clearly and consistently articulated in all reporting
6. Clearly describing the age range of the population surveyed, given the exponential increase in disability after the age of 60. Where the age range of respondents is limited to 49 years and under, as may be the case in a DHS for example, you would anticipate a lower prevalence of disability and to be able to say less about the relationship between disability and violence over a woman's lifetime.

### A standard approach to data analysis

The Washington Group Short Set questions utilise a response continuum in relation to the severity of difficulty in performing an action or activity. The four response options are 'no difficulty', 'some difficulty', 'a lot of difficulty', and 'cannot do at all'. The Washington Group suggest that if any individual respondent answers 'a lot of difficulty' or 'cannot do at all' to at least one of the six Short Set questions, they should be considered a person with disability for data disaggregation purposes (noting, as highlighted on p.4, that this is a proxy measure and that what is actually being measured is functional limitation, which is known to increase the risk of an individual experiencing restrictions in participation if appropriate societal accommodations are not made). In other words, the 'cut-off' used by countries for measuring disability prevalence should be inclusion of individuals who respond that they

have ‘a lot of difficulty’ or ‘cannot do at all’ *to at least one of the functional domains*. Consistency in using this cut-off for reporting disability prevalence is needed to allow cross-country comparison, and is recommended for use in SDG monitoring.

To obtain a disability prevalence figure, response categories can be dichotomized (e.g. individuals reporting ‘a lot of difficulty’ or ‘cannot do at all’ in at least one domain are categorised as one group, and all other respondents are categorised as another group). In the example of a study designed to measure the prevalence of violence against women, this will allow for clarity in reporting of:

- the prevalence of disability among women responding to a household survey looking at violence against women
- comparisons of violence experienced by women with and without disabilities.

While this should be the cut off for reporting, it may be useful for countries to explore the level of violence reported by women who had ‘some difficulty’ in one of the functional domains, to compare this to women who did not report any difficulty functioning in any domain and to women who had a lot of difficulty or could not do at all in one of the domains<sup>3</sup>. If women with even ‘some difficulty’ experience a higher level of violence than women without disabilities, then it would be important to consider how responses to violence against women can ensure that the elevated risk experienced by this group is also addressed.

### Hard to reach’ or ‘easy to ignore’? Strategies to ensure women with disabilities are included in violence surveys

Throughout the workshop the point was made repeatedly that a survey designed to measure the prevalence of violence against women is not able to measure the community-wide prevalence of disability in a particular setting, and determining the prevalence of disability among respondents is not the primary focus of a violence study. However, ‘leaving no one behind’ means it is vital that steps are taken to avoid women with disabilities being excluded from the sample. Women with disabilities are often described as being ‘hard to reach’. However, the SDG agenda requires that this assumption is challenged. Approaches to ensuring that research is accessible to and inclusive to people with disabilities (such as those outlined by Rios et al. 2016) can be adopted by countries conducting studies to determine the prevalence of violence against women. Measures that can be taken to ensure women with disabilities are included in national violence prevalence studies include:

- Training enumerators in the rationale for and use of the WGSS questions when these are included in a violence prevalence study
- Including women with disabilities in the team of enumerators recruited and trained to conduct the violence prevalence study – experience in the region suggests that enumerator teams that include people with disabilities are more likely to identify (and have strategies to address) barriers that may lead to other people with disabilities being under-represented in prevalence studies (Vaughan et al. 2015; Marella et al. 2016)
- Allocating sufficient resources to enumerator training and support to enable an inclusive team (e.g. holding trainings in accessible venues, providing for sign language interpretation in settings where sign language is commonly used)

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<sup>3</sup> If comparing the level of violence reported by women who have ‘no difficulty’ with any of the functional domains with that reported by women who have ‘some difficulty’, ‘a lot of difficulty’ and ‘cannot do at all’, it is important that each group is mutually exclusive – for example, the ‘some difficulty’ group should exclude women reporting ‘a lot of difficulty’ or ‘cannot do at all’. However, if comparing the level of violence reported by women with disabilities to that reported by women without disabilities, women reporting ‘no difficulty’ or ‘some difficulty’ in all domains would be combined as one group (women without disabilities), and women reporting ‘a lot of difficulty’ or ‘cannot do at all’ in **at least one** domain would be combined as one group (women with disabilities).

- Ensuring consent processes are accessible – examples of how to do this include ensuring any written information about the study, including consent forms, is available in easy language version, large print, electronically and can be provided verbally; and that a range of modes of communication and response are accommodated (such as sign language, Braille, screen readers)
- Allocating sufficient resources to the data collection phase to enable a disability-inclusive approach (e.g. having sign language interpreters available, having extra time available for interviewing respondents with communication impairments and/or for interviewing respondents who may more easily become fatigued and require breaks, having enumerators on the team who have had specific training and experience in working with people with communication and other impairments)
- Developing additional strategies to ensure that women with disabilities are able to be safely interviewed in private, including strategies to allow women with communication impairments to communicate directly with enumerators without family members acting as intermediaries (there are specific considerations here, e.g. making sure that women interacting with enumerators through a sign language interpreter cannot be observed, even at a distance)
- Ensuring that any qualitative data collection undertaken to supplement findings from a national violence prevalence study is inclusive of women with disabilities. This may require focus group discussions (for example) with women with different types of impairments to explore experiences of violence that are not captured by the two main survey tools used to measure violence against women.

### Other ways to increase understanding of violence against women with disabilities

**Qualitative** research with women with disabilities may generate a more comprehensive picture of their experiences of violence, generating important evidence for policy and practice in relation to the prevention of, and response to, violence against women. Qualitative methods allow a research team to explore issues such as the nature, severity and frequency of the violence experienced (including disability-specific forms of violence described above); the period of time over which a woman has experienced violence; who perpetrates violence against women with disabilities and in what settings; and the experience of women with disabilities when trying to access help. Qualitative research to better understand these issues, particularly in the context of low- and middle-income countries, could contribute to the development of new or enhanced tools to measure the prevalence of the different forms of violence that women with disabilities particularly face, from a broad range of perpetrators, in the settings where violence against women with disabilities is perpetrated (including state sanctioned violence, such as violence against women in institutions). Such new tools could complement the established tools we have to measure the prevalence of intimate partner and non-partner sexual violence.

Longitudinal research on violence against women is also needed. Longitudinal data is better able to capture the interaction of violence and disability (providing information about whether the onset of violence preceded the onset of disability, or vice versa), and may enable exploration of the intergenerational violence impacts of disability (for example, participants at the meeting noted that mothers of children with disabilities can also experience elevated levels of family violence, and that this is rarely considered in research).

### Addressing additional ethical and safety considerations

All actions taken to address the specific ethical and safety considerations that may be related to disability are underpinned by the knowledge, attitudes and possible prejudices of members of the research team. Therefore it is essential that all members of the research

team, and in particular all enumerators, are provided with disability sensitisation training. This training should aim to raise participants' awareness of what disability is and what disability inclusion requires; build participants' confidence and skills in interacting with people with different types of impairment; and to increase understanding of the violence experiences of women with disabilities, and why it is so important that women with disabilities are included in nationally representative surveys. Increasing enumerator sensitivity to the issue of disability is a necessary first step in preventing women with disabilities being 'screened out' (by either enumerators or household members) during the recruitment of survey respondents. Ensuring that any disability sensitisation training is led by women with disabilities, and that women with disabilities are recruited to be part of the enumerator team, can be an effective way to address the negative attitudes and/or low expectations that research team members may have of women with disabilities.

Following training of the data collection team, close monitoring and support of enumerators is required to ensure that women with disabilities are not being excluded from the study because they are seen to be 'too hard' to interview. Close enumerator supervision is also required to ensure that questions about disability (i.e. the WGSS) are being asked as designed and that questions and response categories are not being adapted in any way.

As described above, specific care needs to be taken interviewing women with communication impairments who usually communicate with the assistance of a family member, and when interviewing women with the assistance of a sign language interpreter. Local Disabled People's Organisations may be able to work with the research team to develop strategies to address these challenges and help ensure interviews are safe.

Safe and ethical practice when conducting surveys on violence against women requires that the data collection team are all aware of response services available in the location where the survey is being conducted, and can make referrals as appropriate. Therefore, it is vital that the research team assess whether the services that they plan to refer women to, if they disclose violence and request support, are accessible to women with disabilities. This may involve working with stakeholders to advocate for modifications and accommodations to be made by services (e.g. installing a ramp into a service that may otherwise be inaccessible), and for resources to be provided for disability sensitisation training for violence service providers.

Disabled People's Organisations can be an important resource for women with disabilities in the community, but very few of these organisations have been trained or resourced to respond to violence against women. The research team can contribute to building relationships, networks and referral pathways between violence response services and disability services to strengthen the sectors' mutual capacity to respond to violence against women with disabilities.

It is well recognised by researchers conducting household surveys on violence against women, that there are contexts where no services are available and where all women have limited access to services and supports. In these contexts it is imperative that the team recognise that there will be even greater barriers to women with disabilities accessing support, and to work with both the violence and disability sectors to develop strategies in response.

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## Appendix 1

<b>Attendee</b>	<b>Organisation</b>
Helen McDermott	DFAT
Felicity O'Brien	DFAT
Corrine Tarnawsky	DFAT
Safiyah Muyeen	DFAT
Henriette Jansen	UNFPA Asia Pacific Regional Office
Kristin Diemer	University of Melbourne
Cathy Vaughan	University of Melbourne
Manjula Marella	University of Melbourne
Alexandra Devine	University of Melbourne
Peta Cox	ANROWS
Jess Cadwallader	Independent disability scholar
Sophia Cason	The Asia Foundation, Timor Leste
Therese Sands	DPO Australia
Robin Butler	Department of Social Services
Caroline Grassia	Department of Social Services
Merridahl Andrew	AWAVA
Deb Loxton	University of Newcastle
Natalie Townsend	University of Newcastle
Sue Salthouse	WWD ACT, Lifeline
Jo Crawford	IWDA
Sharon Bessell	Australian National University
William Milne	ABS, National Centre for Crime and Justice Statistics
Suraksha Maharaj	ABS, Disability, Ageing, Carers and Mental Health Section
<b>Via videoconference</b>	
Jennifer Madans	Washington Group on Disability Statistics
Alessandra Aresu	Handicap International
Davide Olchini	Handicap International

## Appendix 2: Summary of key literature discussed at the meeting

1. **Global** meta-analysis: Hughes K., Bellis M., Jones L. et al. (2012). Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 379(9826), 1621-1629
  - Systematic review and meta-analysis led by researchers at Liverpool and WHO published in 2012 found that between 1990 – 2010 there were 26 published studies reporting prevalence of violence against adults with disabilities over the 12 month period before the study.
  - Pooled prevalence of violence was 24% in people with psychosocial disability, 6% for people with cognitive impairment and 3% in those with non-specific impairments
  - pooled crude odds ratios for the risk of violence against people with disability for people without disability was 1.5 for all studies combined
  - Interpretation: **Adults with disabilities are at a higher risk of violence than are non-disabled adults, and those with mental illnesses could be particularly vulnerable. However, available studies have methodological weaknesses and gaps exist in the types of disability and violence they address. Robust studies are absent for most regions of the world, particularly low-income and middle-income countries.**
2. Research from **Australia**: Krnjacki L. Emerson E., Llewellyn G., Kavanagh A. (2016). Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study. *Australian and New Zealand Journal of Public Health*, 40(1), 16-21
  - Analysis of the 2012 PSS (>17,000 people) **found that people with disabilities were significantly more likely to experience all types of violence, both in the past 12 months and since the age of 15.** Women with disabilities were more likely to experience sexual and partner violence and men were more likely to experience physical violence.
3. Research from **Cambodia**: Astbury J, Walji F. (2014). The prevalence and psychological costs of household violence by family members against women with disabilities in Cambodia. *Journal of Interpersonal Violence*, 29(17), 3127-49
  - Triple Jeopardy (funded by AusAID through an ADRA and conducted by Monash University, CBM Australia, IWDA, Banteay Srei and the Cambodian Disabled People's Organisation). This was not a population based study but involved the recruitment of women with disabilities identified through Disabled People's Organisation partners and then recruitment of women without disabilities from the same communities to enable matching based on geographical location and socioeconomic status. Survey results showed no significant difference between women with disabilities and women without disabilities in the prevalence of physical or sexual violence perpetrated by a partner, meaning that **women with disabilities are just as likely to experience violence from a partner as women without disabilities. However, women with**



- disabilities were up to 4.2 times more likely to experience controlling behaviour from partners.** Kessler findings indicate high levels of psychological stress for women with disabilities
- **There were statistically significant differences between women with and without disabilities, and family (non-partner) violence.** More than half (or 52.5 per cent) of the women with disabilities who participated in the survey (n = 177) reported emotional abuse, 25.4 per cent reported physical violence, and 5.7 per cent reported sexual violence from family members. This was in addition to an array of controlling and coercive behaviour including having to seek permission from others in the family before accessing health care. These prevalence rates were all statistically significantly higher than those experienced by women without disabilities.
4. Research from the **Philippines**: Vaughan C., Devine A., Ignacio R. et al (2016). Building capacity for a disability-inclusive response to violence against women and girls: experiences from the W-DARE project in the Philippines. *Gender & Development*, 24(2), 245-260
- Women with Disabilities taking action on sexual and Reproductive health (W-DARE) was also funded by DFAT through an ADRA, with additional support from the UNFPA Philippines Country Office. The project aimed to investigate ways to improve access to sexual and reproductive health and violence response services for women and girls in the Philippines (University of Melbourne partnership with De La Salle University, WOWLEAP, PARE, Likhaan Center for Women's Health)
  - Qualitative interviews reported violence from a wide range of perpetrators, including those in a position of service (e.g. transport workers, teachers, and health workers)
  - Interviews with 42 women and girls with disabilities found that violence was common and was one of the highest priorities of the women with disabilities and DPOs involved in the study
  - Limited awareness of rights, lack of awareness of services and sources of help, communication barriers, lack of response from services and poor access to justice. **Women with particular types of disability reported both severe violence and severe barriers to services**, and this was in particular women who were deaf, women with intellectual disabilities and women with psychosocial disabilities.
  - **Similar to what was found in Cambodia, women with disabilities reported violence from a range of perpetrators – not just intimate partners, though that was there, but also other family members, neighbours, strangers, teachers, transport providers, and health workers**
5. Research from the **Pacific**: Spratt J. (2013). *A Deeper Silence: the unheard experiences of women with disabilities - sexual and reproductive health and violence against women in Kiribati, the Solomon Islands and Tonga*. Suva: UNFPA Pacific sub-regional office.
- Interviews with women with disabilities found they had experienced physical and sexual violence. Some reported experiences of violence at the hands of intimate partners and caregivers. Others reported rape by

strangers or acquaintances, including during the critical developmental years of adolescence.

- **The consequences of violence can be severe.** Some of those interviewed reported that violence increased during pregnancy. The project also found that women with disabilities require more support when they experience violence and seek assistance.
- Women with disabilities experience different forms of violence from women without disabilities. These include acts such as the withholding of medication and assistance, denial of food or water, and forced sterilization and medical treatment.

6. Research from **Timor-Leste**: The Asia Foundation (2016). *Understanding violence against women and children in Timor-Leste: Findings from the Nabilan Baseline Study – Main Report*. Dili: The Asia Foundation.

- Presented by Sophia Cason from the Asia Foundation at the consultation
- During the Nabilan survey on violence against women, five of the six Washington Group short set of questions on disability were included in the questionnaire tool. This enabled the research team to analyse associations between violence and disability
- **Women who had experience physical and/or sexual intimate partner violence were significantly more likely to report ‘a lot of difficulty’ or ‘cannot do at all’ to at least one of the WGSS questions (adjusted odds ratio 2.5)**
- Noted that the **association between risk of disability and experience of violence is likely to be bi-directional** (women with disability are more likely to be experience violence, and women who experience violence are more likely to have or acquire disability).