



## Triple jeopardy: Ethical considerations in researching violence against women with disability in Cambodia

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### 1. SUMMARY OF RESEARCH AND PARTNERS

The research project *Triple Jeopardy: Violence against women with disabilities in Cambodia*, explored the experiences and prevalence of gender-based violence (GBV) among women with disabilities, how this compared to other women, and barriers to accessing support. The research was a partnership between International Women's Development Agency (IWDA), CBM Australia, Monash University, the Cambodian Disabled Persons Organisation (CDPO) and Banteay Srei, a Cambodian women's organisation. It was funded through a three-year Australian Government Australian Development Research Award, with follow-up activities supported through the Australian Government's Australian Leadership Awards program, the Australian NGO Cooperation Program, and through the ongoing work of partners.

### 2. RATIONALE AND PURPOSE

Worldwide, disability is more prevalent among women than men, with prevalence among women higher in lower income countries (WHO & World Bank 2011, p. 28). Women and girls living with disability in developing contexts face multiple and intersecting sources of discrimination: being female, having a disability and being among the poorest of the poor (UNFPA, 2005). Disability compounds gender inequality (World Bank 2011, p.55) with women and girls with a disability often at greater risk of violence, injury, abuse, neglect, maltreatment or exploitation (United Nations, 2006). However, there is little precise disability- and sex-disaggregated data on interpersonal violence, constraining understanding and response. While data on interpersonal violence against women has improved, particularly following publication of the WHO's 2005 *Multi-country Study on Women's Health and Domestic Violence against Women* and subsequent studies using this methodology, data currently cannot be disaggregated by disability.

Data reporting disability in Cambodia is variable; the 2008 Population Census reported disability prevalence at 1.4%, compared to 6.3% in the 2009 UN socio-economic survey (UNESCAP, 2012, p.12). Both figures are much lower than the global estimate of 15%. Cambodia is estimated to have one of the highest rates of disability in the developing world (World Bank 2007, UNESCAP, 2002). Women with disability are particularly marginalised from development activities, underserved by both disability and women's organisations.

This research was designed to address the gaps in evidence and give voice to the experiences of women with disabilities. Women with lived experience of disability and gender inequality were hired as researchers, respecting the principle of 'nothing about us without us'. This contributed to research quality and accuracy, giving participants confidence that their experience would be heard and understood.

The project was led by a researcher with expertise in researching violence against women, and based on current best practice (Elseberg & Heise, 2005; WHO, 2005). The mixed-methods investigation was used to ensure multiple perspectives on GBV. Participatory techniques were used to collect qualitative data through:

- 15 key informant interviews, including with legal service providers, government, DPOs, other NGOs.
- Focus group discussions (8 x 10) and in-depth interviews (30) with women with disabilities, to assess knowledge and attitudes to violence against women with disabilities, and community-level barriers and



facilitators to appropriate services.

- A survey of 354 women with and without disabilities which integrated benchmark survey tools, to facilitate confidence in and comparison of data, and to use in other contexts: the WHO Multi-Country Survey Tool on gender equality and violence against women; the Washington City Group Questions on Disability (to screen for functional disability); and the WHO Self-Report Questionnaire, a well validated measure of common mental health disorders.
- Documentation was gathered of field researchers' insights into how to improve the situation for women with disability who experience violence.

### 3. ETHICAL CHALLENGE

Given their marginalisation and vulnerability in Cambodia, researching GBV against women with disabilities raised critical ethical issues. In particular, conducting the research required considerable attention to issues of risk and safety, justice and benefit, and informed consent.

The research addressed the issues often faced by women with a disability including invisibility, marginalisation and neglect. Critical challenges included enabling highly marginalised women with disabilities to feel safe to contribute their experiences without putting them at further risk; providing support to women disclosing violence in a resource-constrained context; and protecting the safety and psycho-social health of researchers.

Closely related are the ethical concepts: justice; ensuring that the research delivered an accurate picture of the prevalence of violence against women with disabilities and benefit; and ensuring that the personal risk in participation was balanced by a benefit in outcomes. Addressing some ethical challenges created others: using questions to screen for functional disability rather than asking participants to self-identify created its own exclusion through informed consent as steps to ensure the safety and voice of individual women meant excluding those who required a third party to facilitate or consent to their participation. This meant that, for example, deaf women with no sign language were excluded as were women with an intellectual disability.

### 4. RESPONSE AND APPROACH

Responding to the ethical considerations noted earlier shaped all aspects of the research. Steps were taken to respond to ethical issues.

1. **Including gender- and disability-focused organisations in the partnership** embedded sensitivity to gender and disability considerations in line with the principle of 'nothing about us without us'. The partnership approach enabled both disability- and gender-specific organisations to grow in their understanding of issues and their intersectionality over time.
2. **Accessibility** was a core criterion for the project office and training venues.
3. **Hiring women with disabilities as field researchers** demonstrated women with disabilities in professional roles and enabled participants and the wider community to envisage alternative futures. The project invested in strengthening the capacity of local partners to develop and conduct qualitative and quantitative participatory research related to disability, gender inequality and violence. All local researchers now have ongoing paid roles in the partner organisations.
4. **Maximising opportunities for women with disabilities** as content developers and training facilitators resulted in participants being compensated for their time, recognising the opportunity costs of



involvement in the research.

5. **Pairing female researchers worked to maximise safety and build understanding** regarding gender and disability. The project purchased vehicles and hired male drivers who also acted as unofficial protectors, remaining close enough to hear if there were any safety problems but not so close as to overhear interviews, though at times researchers still reported feeling unsafe. Another protective measure for both researchers and participants was to introduce the research to communities as women's health research.
6. **Interviews were conducted in private places.** However, researchers also carried a 'dummy' survey, missing questions on violence, in case interviews were interrupted.
7. **Ensuring ongoing informed consent** included regularly checking whether participants wanted to continue during interviews and surveys, including explicitly seeking consent to proceed to questions about violence. At the end of each interview, most participants confirmed that participation had been a positive experience. This is consistent with evidence that talking about experiences of violence, and being listened to, is, in itself, valued by women, especially if participants see it as a way of helping other women in the future. Researchers provided information about violence support services to women who required it, if these were available. The research partners included NGOs with ongoing engagement in many of the research communities.
8. **Strategies to provide psycho-social support to researchers** included not scheduling too many interviews in one day and holding interviews on four days only, building in time for debriefing, reflection and data entry. A workshop on researcher self-care was conducted at an early training workshop and Social Services Cambodia was contracted to provide ongoing support to the local research team.

## 5. OUTCOMES AND ONGOING CONSIDERATIONS

### Key findings

- In comparison to other Cambodian women, women with disabilities in Cambodia experience much higher levels of controlling behaviours from partners and significantly higher levels of all forms of violence (emotional, physical and sexual) from family members other than partners.
- The intersection of gender and disability changed the *nature* of the violence experienced by women, with women with disabilities more likely to experience family violence than intimate partner violence. This underlines the importance of researching violence in a way that includes women with disabilities.
- Women with disabilities report significantly higher levels of psychological distress than other women, regardless of level of exposure to violence.
- Barriers to disclosure and access to services are worsened by the fact that many women with disabilities have less mobility, financial autonomy and power than other women.
- There is an urgent need to improve policies and services to prevent and respond to violence and discrimination experienced by women with disabilities, particularly family violence.
- Levels of psychological distress experienced by women in Cambodia are extremely high nationally, pointing to an urgent need for improved and extended mental health services that are trained to deal with the different needs of women with disabilities.

The research also highlights the value of partnership between research institutions and NGOs in achieving



transformative outcomes; the partnership enabled rare insight into the lived experience of women with disabilities for the academics involved, and provided capacity building within NGOs and for women with disabilities. Further, through working in partnership, the research has revealed key steps and processes for addressing the ethical challenge of benefit, particularly when conducting research with vulnerable populations. Partner organisations have resourced follow-up activities to support the translation of research findings into programming, including training and structured leadership and strategic planning work with representatives from government, NGOs and academia in Cambodia. Of most benefit was the practice of hiring and training women as researchers which has provided marginalised women, their families and communities with a powerful role model of what is possible for women with disabilities when given the right support.

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