



Ethical considerations for disability-inclusive gender-based violence research?

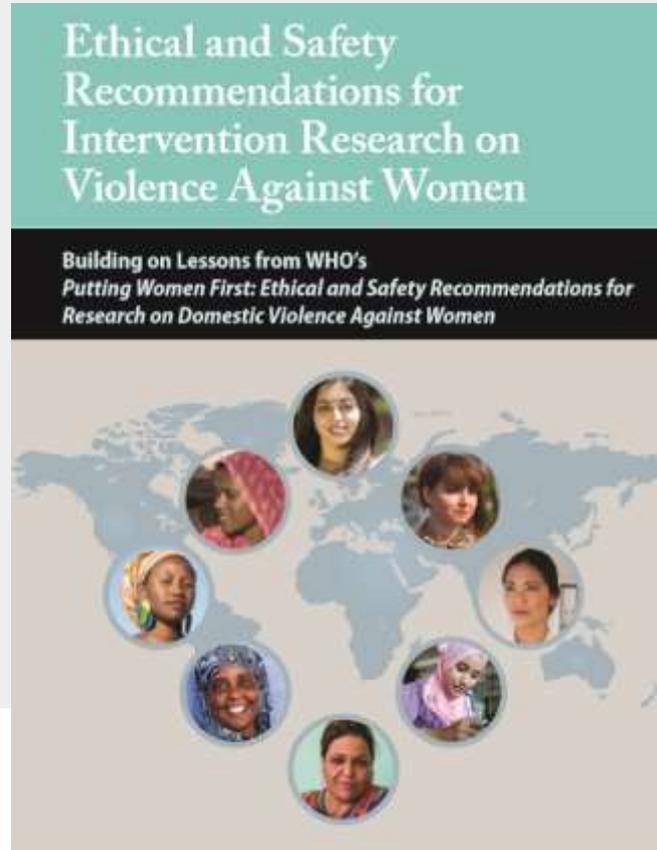
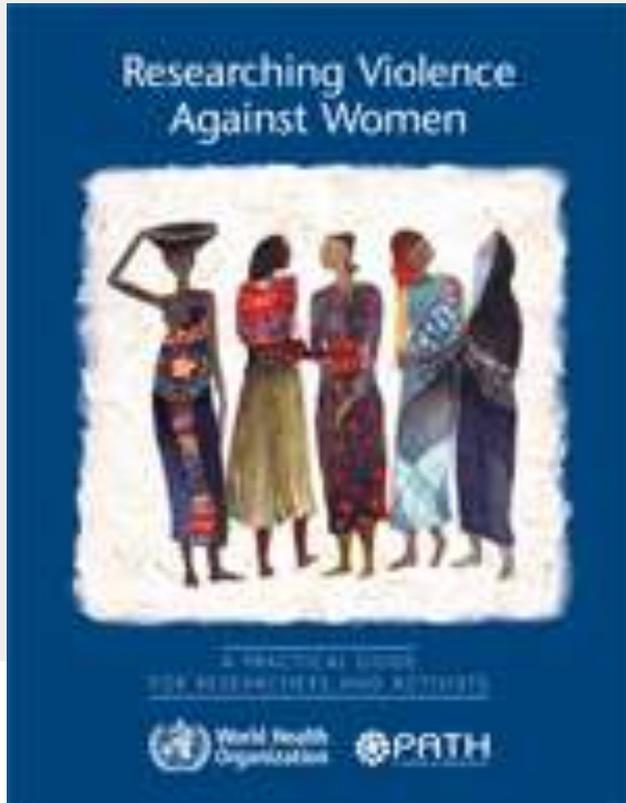


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Is it not **ethical** to recognize the rights of all people with disabilities to be included in research, while simultaneously protecting them from harm.



LACK OF FORMALIZED GUIDELINES FOR INCLUSIVITY



STUDY ON VIOLENCE EXPERIENCES OF WOMEN WITH PHYSICAL DISABILITIES

- Lessons learned from South African qualitative study (2014 – 2017)
 - N=30; women, physical, hearing and sight difficulties,
- Ethically approved.

EXPECTED AND UNEXPECTED ETHICAL SHORTCOMINGS...

TRAINING

- Plan and budget for training Diversity and rights, challenging stigma, inclusive communication/interaction, and how to accommodate needs?
- Requires expert consultation / partnerships
- Constantly evaluate
 - Does it improve inclusion, protection, retention, and data quality?
- Let it inform guidelines

REASONABLE ACCOMMODATION

- Anticipate environmental barriers
 - ensure access during interviews, specialized transport, interpreters
- But also continue to ask and accommodate
 - fluctuating needs for comfort
- Fatigue, pain, impact of weather on participation



ACCESSIBLE CONSENT

- Autonomous – no supportive decision making (capacity to consent - severe and cognitive)
- **Ask** them how *they* want to communicate, accommodated (PWD are their own experts)
- Flexible in written, oral, or pictorial consent
- Informed consent - accessibility of ONGOING consent (check-in/**ask** to explain back)

INTERMEDIARIES – AN ETHICAL DILEMMA?

- Pro – recognize disability-related needs/discomfort
- Con - Potential perpetrators?
- Self nominate for trust and rapport
- Confidentiality pledge – avoid sharing details
- **Ask!** Still comfortable with intermediary?

ANOTHER LESSON LEARNT...

- Online survey with assistive technologies built in may have
- Facilitated disclosure (no intermediaries)

ACCESSIBLE AND APPROPRIATE REFERRALS

- Can GBV services/referals cater to a spectrum or a specific disability.
- Ask disability partners to facilitate referrals
- Limitation – did not follow up!
- Conduct an inclusivity audit of GBV services before using them as referrals

SHORTCOMING: DISSEMINATION AND UPTAKE STRATEGY FOR FINDINGS

Budget for consultation of accessible / augmentative dissemination and research translation

Evaluate it! Does it reach DPOS, researchers, programmers & policy makers,

THEY CAN AND THEY WANT TO

- Ask reflective questions about the research process – what did I do wrong?
- Participation can happen
- Feel included in violence prevention –
- We need guidelines for future protection

TAKE HOME MESSAGES

ASK and try to learn about the shortcomings and accommodate – “they are their own experts” in facilitating inclusion

With enough training and energy, we can get information from an often silenced population and add to data

Draw on lessons learned in the field and disability expertise – WHAT WORKS?

Thank you.