

Terms of Reference

The right to informed consent and persons with disabilities

Technical Unit	GHD - HQ	Location	Home based/teleworking
Function	Informed Consent Consultant	Technical field	Global Health
Name of HR advisor	Jane Newnham	Name of technical unit director	Alessandra ARESU
Length of the mission	From Sep to Dec 2021	Name of technical specialist	Jane Newnham
Duration of funding of the position	30 days of consultancy	Reason for recruitment	Development of tool kit for informed consent

Job reference	Informed Consent Consultant
Classification	Individual / team consultancy
Minimum experience	5 years
Request date	09/08/2021
Preferred start date	06/09/2021
End date of predecessor's mission	N/A
Preferred duration of handover	N/A

PRESENTATION OF HUMANITY & INCLUSION:

Outraged by the injustice faced by people with disabilities and vulnerable populations, we aspire to a world of solidarity and inclusion, enriched by our differences, where everyone can live in dignity.

Humanity & Inclusion / Handicap International (HI) is an independent and impartial aid and development organization with no religious or political affiliations operating in situations of poverty and exclusion, conflict, and disaster. We work alongside people with disabilities and marginalized people to help meet their essential needs, improve their living conditions and promote respect for their dignity and fundamental rights. For further information: www.hi.org

CONTEXT OF THE CONSULTANCY

Health services, including Maternal Newborn and Child Health (MNCH) and Sexual and Reproductive Health (SRH) services are a fundamental human right, and should be provided on the basis of free and informed consent to women and girls, men and boys and people in all their diversity, including persons with disabilities. The necessary information to exercise such consent must be conveyed in a reasonable, accessible and understandable manner. According to Article 12 of UNCRPD¹, people with disabilities have the same right to make their own decisions about important things as everyone else. They should have the proper support they need when making decisions. If a person really does need someone else to speak for them there should be rules to make sure this is done properly.

¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Women and girls with disabilities face challenges in exercising their rights to SRH services that are unique from and disproportionate to other women and to men and boys with disabilities. Women and girls with disabilities' fundamental right to informed consent is often violated as a result of ignorance, lack of awareness, stigma, misconceptions, and lack of inclusive tools and accessible information². Women and girls with disabilities, in all their diversity, are at higher risk of invasive obstetric procedures, and may experience forced sterilisation, abortion, contraception, female genital mutilation, and obstetric violence within their communities and health services³. Such procedures performed without informed consent from the person with a disability can amount to physical, sexual and psychological gender-based violence (GBV) as well as cruel, inhuman and degrading treatment or punishment (CIDTP). Women and girls with intellectual disabilities, including developmental disabilities, and persons with mental health and psychosocial disabilities face increased challenges in exercising their SRHR and accessing services, and a higher risk of experiencing GBV. There is a lack of focus on these populations' rights to safe and informed SRH services and the specific legal, ethical and systematic barriers that they face.

Ongoing projects on inclusive health, including inclusive MNCH, SRH and GBV prevention do not provide persons with disabilities, caregivers, family members and service providers with the knowledge and the tools needed to ensure persons with disabilities, and especially women and girls' right to informed consent is fulfilled and that the principle of 'Do no harm' is respected.

OBJECTIVE OF THE CONSULTANCY

The overall aim of the consultancy is to increase the awareness of a Human Rights based approach to informed consent for SRHR/MNCH services, including GBV management for HI field staff, SRHR service providers, and decision making capacities of persons with disabilities as well as carers and family members.

The objective is to develop a global guideline, training materials and information education and communication materials to inform more inclusive and ethical SRH [and GBV] services in LMICs and humanitarian settings.

The guideline should be based on a systematic review of literature and resources and informed by persons with disabilities and their representatives, and supplemented with training materials for field staff and service providers for supporting HI programs. Resources will also be produced for persons with disabilities and support persons and family members to increase awareness on the rights of persons with disabilities to informed consent for SRH services.

SCOPE OF WORK

The consultant will be required to conduct the following tasks:

1. Conduct a **desk review on** relevant literature and resources around persons with disabilities and informed consent for comprehensive SRH services, including medical and mental health care for GBV survivors with disabilities – 4 days
 - Include legal frameworks, competency assessments, investigation of key issues such as forced sterilisation; abortion; contraception; pregnancy, SEAH and obstetric violence
2. Conduct **key informant interviews** with key staff, and field actors in specified countries (2 countries from East and West Africa) through partners to identify good practices, key issues

² Groce, N. (2009), Key Concepts in Disability. Global Disability. Special Issue, The Lancet. 2009.

³ Frohmader, C; Ortoleva, S. The Sexual and Reproductive Rights of Women and Girls with Disabilities, Issues Paper, 2013

and gaps in knowledge and resources for obtaining informed consent for SRH services from persons with disabilities including persons with intellectual disabilities.

3. Conduct **FGD or KIIS** with women and girls with all forms of disabilities including persons with intellectual disabilities (knowledge on what is consent, satisfaction of service providers, experience of violence in health care facilities) through in country partnerships- 11 days (total time for task 2 and 3).
4. Produce accessible summary guidelines for describing important considerations around obtaining informed consent from persons with disabilities (different age groups and types of disabilities). The target audience for the guide is HI program managers, technical staff and health care workers- 5 days.
5. Develop, test and adapt **1 day training module** (PPT and facilitators guide) to accompany summary guide. Include - target audience HI staff and service providers- 6 days
6. Develop Information, Education and Communication material around persons with disabilities rights and informed consent which can be adapted to different contexts- Materials to be produced for Health workers as well as carers and family members- 3 days

METHODOLOGY and TIME FRAME

This consultancy is a home-based position. The consultant will liaise virtually/online with in-country partners for KIIs and FDGs. T

To complete the proposed tasks, the consultancy is estimated to take up to 30 days spread over a maximum of 3 month period (starting first half of September 2021) as outlined below:

- Briefing / coordination meetings / debriefing – 1 days
- Desk review - 4 days
- Liase with and train in country field staff to conduct interviews with field staff, service providers and persons with disabilities plus report of key findings – 11 days
- Guidelines – 5 days
- Training module – 6 days
- Development of IEC material- 3 days

DELIVERABLES

- Briefing and coordination meetings minutes;
- Interview tool development
- Transcripts from interviews and FGD's
- Desk review/KIIS report (maximum 10 pages) to highlight key issues, gaps in knowledge and resources
- Summary guide – key considerations to obtain Informed consent for SRHR services for persons with disabilities (maximum 10 pages)
- 1 day training module- PPT slides, facilitators manual (including pre and post training test, supervision tool) and participants' manual- English, French, Spanish
- IEC material for two different audiences – Health Care Workers and persons with disabilities and carers/family members- English, French, Spanish

The deliverables should be submitted in academic English. A reasonable use of figures, tables, and other graphic visualization is encouraged. All deliverables should use a Vancouver style referencing with updated links.

All deliverables should demonstrate concrete efforts to decolonizing knowledge, including critical views as well as Global South voices and sources.

PROFILE REQUIRED

The consultant should possess relevant experience in undertaking a task of similar nature and magnitude, and shall have the following qualifications and experience:

- Advanced university degree in Human Rights/Public Health/ Law;
- At least 5 years of experience of working on issues around a human rights approach to SRH/GBV and persons with disabilities;
- Experience working in humanitarian and development settings, at global and country level;
- Direct experience working with persons with disabilities is an asset
- Proved experience on publish research and/or writing technical guidelines;
- Commitment and knowledge of health equity, diversity and inclusion, and participation under disability, gender and age lens;
- Demonstrate clarity, accuracy and an ability to summarize;
- Strong interpersonal and intercultural skills;
- At ease with distance (virtual/online) work with teams, good communication skills;
- Rigorous, organized, pragmatic;
- Fluency in English and French a pre requisite

HOW TO APPLY:

Email applications should be addressed by 23/08/2021 to Jane Newnham j.newnham@hi.org indicating in the subject of the e-mail: “Consultancy for Informed Consent“

The submission should include:

- Cover letter (maximum one page)
- Financial proposal (in Euros);
- Curriculum vitae (CV)
- Relevant education certificates
- Two evidence of previous similar work (e.g. policy, technical guidance, manual training, etc.);
- Names and contact information of three references;
- Request for reasonable accommodations if needed.

Only candidates who meet all qualifications and experience will be contacted for further consideration. HI is committed to preventing any type of unwanted behavior at work including sexual harassment, exploitation and abuse, lack of integrity and financial misconduct; and committed to promoting the welfare of men and women with and without disabilities with whom HI engages. HI expects all staff and partners to share this commitment through our code of conduct and other Institutional policies such as the PSEAH and Child Protection Policy. Women with disabilities from LMICs or humanitarian contexts are highly encouraged to apply.