



# Sexual and Reproductive Health and Disability: Examining the Needs, Risks and Capacities of Refugees with Disabilities in Kenya, Nepal and Uganda

## Introduction

In 2013, 51.2 million people were forcibly displaced by conflict and persecution,<sup>1</sup> and 22 million were displaced by natural disasters.<sup>2</sup> The World Health Organization (WHO) estimates that 15 percent of the global population are persons with disabilities.<sup>3</sup> This figure is likely to be higher in situations of humanitarian crisis due to conflict-related injuries and the breakdown of health systems.

There is a growing body of literature that recognizes that persons with disabilities have historically been denied their sexual and reproductive health (SRH) rights.<sup>4</sup> They may have less access to SRH information, which is necessary for healthy and safe relationships, protection from HIV and other sexually transmitted infections (STIs), and realization of autonomy in family planning decisions.<sup>5</sup> Reports further highlight the multiple and intersecting forms of discrimination that women with disabilities often experience, many of which increase their vulnerability to different forms of violence, including gender-based violence (GBV).<sup>6,7</sup>

The needs of women, girls, men and boys with disabilities are notably absent from global SRH and gender guidance for humanitarian response. The standard guide for SRH in emergencies, the Inter-agency Working Group (IAWG) on Reproductive Health in Crises' 2010 *Inter-agency Field Manual on Reproductive Health in Humanitarian Settings*, does not address issues of equitable SRH access for persons with disabilities, or the specific SRH vulnerabilities and risks faced by this particular group.<sup>8</sup>

## Sexual and reproductive health of persons with disabilities

Article 25 (a) of the Convention on the Rights of Persons with Disabilities (CRPD) declares that persons with disabilities should have the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health (SRH) and population-based public health programs.

Few programs are currently available, however, to address the SRH needs of persons with disabilities. Understanding their unique needs, risks and capacities can better ensure that the humanitarian SRH community addresses their SRH rights.

## Background

To address this information gap, the Women's Refugee Commission (WRC) led a participatory research project with partners to explore the intersections between SRH and disability in the humanitarian contexts of Kenya, Nepal and Uganda. The study explored the specific risks, needs and barriers for persons with disabilities to access SRH services in humanitarian settings, and the capacities and practical ways through which challenges can be addressed.

Per the CRPD, "persons with disabilities" are defined as those who have "long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others."<sup>9</sup> "Barriers" are described as environmental, attitudinal or structural barriers that impeded access to services.<sup>10</sup> "Sexual and reproductive health" encompassed the International Conference on Population and Development (ICPD)

definition to include maternal and newborn health, family planning, STIs, including HIV, and GBV.<sup>11</sup>

Funded by an anonymous donor, the goal of the study was to enhance and improve programs for persons with disabilities in humanitarian settings. The WRC coordinated the study. Local partners — International Rescue Committee (IRC) in Kenya, Refugee Law Project (RLP) in Uganda and the Association of Medical Doctors of Asia-Nepal (AMDA Nepal) — facilitated the ethical approval process in each country. Partners also participated in data collection and reviewed written outputs.

## Study locations

The study was implemented in three locations where conflict-affected refugees live. Site selection was based on availability of SRH programs, regional diversity and capacity for implementation.

**Kenya:** The study was undertaken in Kakuma refugee camp in Kakuma, Kenya. Established in 1992, the camp hosted 105,000 refugees from 13 countries in 2013, primarily from Somalia (49%), South Sudan (31%), Ethiopia (6%), Democratic Republic of Congo (5%), Sudan (4%) and Burundi (3%). IRC – the primary provider of comprehensive SRH services in Kakuma refugee camp – hosted the study. At the time of the study, 2,084 refugees were registered as having disabilities among a total camp population of 128,560 persons, representing approximately 1.6% of the total population. Study participants were consulted in Somali, Kiswahili, Arabic, English and Somali sign.

**Nepal:** The study was undertaken in Beldangi refugee camp (I, II and Extension) in Damak. As of August 2014, there were 25,433 Bhutanese refugees in Beldangi and Sanischare Camps. AMDA Nepal and the United Nations High Commissioner for Refugees (UNHCR) hosted the study, in partnership with the Nepal Disabled Women Association (NDWA), the National Federation of the Disabled Nepal (NFDN) and the Damak Disability Helping Committee (DDHC) – NFDN's local chapter. As of March 2014, 854 persons with disabilities were living in the camps, representing approximately 3.4% of the total population. Participants were consulted in Nepali and Nepali sign.

**Uganda:** Kampala is host to more than 46,000 refugees, primarily from the Democratic Republic of Congo (DRC), Rwanda, Somalia, Burundi, South Sudan, Ethiopia and Eritrea. Refugees are scattered throughout the city's slums, with Somalis concentrated in the central neighborhood of Kisenyi and Congolese in Katwe, Makindye and

Masajja. RLP, which provides counseling, social services, income generation, advocacy, research and capacity-building, hosted the study. According to UNHCR, as of June 2013, there were 452 registered refugees with disabilities in Kampala. Participants were consulted in Swahili, Somali, Kinyarwanda and Luganda sign.

## Research process

The study employed a two-stage process to maximize participatory involvement by persons with disabilities and stakeholders in the research design.

### I. Consultative phase

The first phase built the foundation of the study through consultations with stakeholders and informants in each setting. Conducted over the course of a year in advance of study implementation, the WRC traveled to each site to convene agencies servicing refugees, organizations of persons with disabilities (DPOs) and refugees with disabilities to solicit input to the study design. The consultative trips resulted in the identification of co-investigator partner agencies, as well as the formation of local advisory groups that guided the study design, tools development, study implementation and data interpretation processes.

### II. Study implementation

Based on input from the local advisory committees, questions were developed that explored the experiences and perceptions of refugees with disabilities on: specific SRH needs and risks; barriers and challenges to accessing SRH services; perceptions of services; impact of stigma and caregiver/provider attitudes; protection strategies; and capacities and resources to meet SRH needs and protect from SRH risks.

The target populations selected for this study were:

- Refugees who self-identified as person with disabilities and had been displaced. This included persons with **physical, intellectual, sensory and mental** impairments in the following age groups:
  - » Refugee women of reproductive age with disabilities (20-49 years)
  - » Refugee men with disabilities (20-59 years)
  - » Refugee adolescent girls with disabilities (15-19 years)
  - » Refugee adolescent boys with disabilities (15-19 years)

	Women of re-productive age (20-49 years)	Men (20-59 years)	Adolescent girls (15-19 years)	Adolescent boys (15-19 years)	Caregivers/ family members	Total
<b>Kenya</b>	41	23	20	11	17	112
<b>Nepal</b>	40	29	10	10	15	104
<b>Uganda</b>	50	17	24	12	33	136
<b>Total</b>	<b>131</b>	<b>69</b>	<b>54</b>	<b>33</b>	<b>65</b>	<b>352</b>

	1. Refugees with physical, vision and mild mental impairments	2. Refugees with hearing impairments	3. Refugees with mild intellectual impairments	4. Other refugees (home-based, new mothers, etc.)
<b>Kenya</b>	60	15	11	9
<b>Nepal</b>	30	38	16	5
<b>Uganda</b>	70	3	24	6
<b>Total</b>	<b>160</b>	<b>56</b>	<b>51</b>	<b>20</b>

- Caregivers/family members who care for adolescent or adult refugees with disabilities

Participatory activities with refugees with disabilities included: body mapping,<sup>12</sup> timelines<sup>13</sup> and sorting<sup>14</sup> to explore knowledge of the reproductive system and fertility; examining community perceptions surrounding persons with disabilities and their SRH; identifying barriers to accessing information and services; examining perceptions around different types of treatment; and determining risk and protective factors. Activities with families/caregivers spurred discussion regarding new experiences and concerns that emerge as a result of a child maturing into a teenager or an adult, and experiences seeking health care for their child/family member with disabilities.

To maximize inclusion, all sites engaged refugees, refugees with disabilities or other persons with disabilities to serve as part of the study team.

## Learning, at a glance

Preliminary findings revealed common and disparate findings across the three settings:

- Awareness of SRH:** In all three settings, refugees with disabilities demonstrated varying degrees of awareness around SRH, especially regarding the reproductive anatomy, family planning and STIs. HIV and condom use for HIV prevention were most widely known across countries, age, sex and impair-

ment group. Adolescents with access to schooling in Kenya and women already using contraceptives in Nepal generally had better knowledge of SRH, especially around family planning methods. Lack of awareness and misconceptions were apparent among those without such opportunities – especially refugees isolated in their homes, some of whom in Uganda were not familiar with sexual intercourse as a concept – as well as refugees with intellectual impairments. Despite awareness gaps, persons with disabilities across age, sex and impairment group – particularly women and adolescents – showed much interest in learning more about SRH.

- Experiences around use of health/SRH services:** Provider attitudes were often reported as the most significant barrier deterring refugees with disabilities from accessing health and SRH services. In Nepal, Bhutanese refugees with disabilities and their caregivers reported fewer attitudinal problems in areas where major improvements had been made in the past 18 months as a result of UNHCR, WRC and NDWA's efforts to address disability inclusion. However, in Uganda, negative provider attitudes were a critical problem at both of the agencies serving refugees, the Kampala Capital City Authority Health Centers and the national referral hospital. Participants in all three countries reported that among the barriers to accessing services – such as long wait times (Kenya and Uganda), costs of seeking care

(Uganda), refugee status (Uganda), provider communication challenges (all three sites) and limited accessibility (all three sites) – lack of respect by providers was often the most hurtful barrier.

- **Experiences around romantic relationships:** Participants in Kenya and Uganda said that it was natural for adolescents with disabilities to have romantic relationships. In Nepal and among Somali refugees in Kenya and Uganda, premarital relationships were generally scorned by women and girls with disabilities. Some adolescent girls in Nepal were distrustful of relationships, noting that they could be “cheated” due to their disability.
- **Experiences of women and girls with disabilities who become pregnant:** Pregnant women with disabilities were often discriminated against by providers and scolded by caregivers for becoming pregnant and bearing children. Providers in Uganda were often said to make derogatory remarks, while some caregivers in all settings were reportedly concerned about the additional responsibilities they would incur when their family member bore children. In Uganda and Nepal, several women with disabilities were observed to have less stable relationships and were subsequently caring for children without a partner, raising protection concerns.
- **Safety concerns:** Refugees with disabilities across sites reported that the lack of physical accessibility contributed to the lack of safety. Risks of sexual violence prevailed across sites, including for persons with hearing disabilities in Nepal. Adolescent girls in Kenya and Nepal also alluded to risks of molestation. Caregivers were concerned about sexual violence against their family members, especially those with intellectual disabilities. Participants in Kenya were most aware of the benefits of seeking medical care after experiencing sexual assault, while participants in Nepal were least familiar.
- **Ability to exercise SRH rights:** The ability/autonomy of women with disabilities to exercise their SRH rights was mixed, ranging from full autonomy to none. Participants in Uganda mentioned the possibility of forced abortion for women and girls with disabilities who had unplanned pregnancies, or forced use of family planning methods. In all three sites, however, marital status was reportedly the largest factor that determined how women and girls with disabilities would be treated and received by their

families and neighbors if they became pregnant.

- **Protective factors:** While physical and sexual risk factors are widespread for refugees with disabilities, home-based participants in Kenya and refugees with mental impairments in Uganda cited protective resources – especially caregivers, counselors and activities – that offered emotional and mental respite.
- **Recommendations from participants:** Improvements in their health care experience, as well as activities to empower themselves, were among the commonest recommendations offered by refugees with disabilities to improve their SRH experience. Suggestions included training providers on respectful communication skills with persons with disabilities; employing sign language interpreters in health facilities; expanding SRH awareness-raising activities; and providing spaces for peer learning, as well as leadership, skills building and income-generation opportunities.

## Overarching recommendations

**Donors and governments supporting agencies that service refugees** should:

- facilitate disability inclusion among agencies they support by providing funds for staff/provider learning opportunities; creating incentives to develop programming partnerships with agencies that have disability inclusion expertise; and facilitating increased national, regional and global dialogue on improved SRH service quality and enhanced outreach to refugees with disabilities;
- support agencies to promote or facilitate the empowerment of refugees with disabilities and their families in their communities through providing funds for income generation, vocational training, SRH education and other learning opportunities; and
- promote reflection and accountability on disability inclusion through monitoring and reporting processes.

**Agencies serving refugees**, including through providing SRH services, should:

- address disability as a cross-cutting issue, similar to gender considerations;
- allocate a budget line for disability inclusion so that they can be adaptive and flexible in their approach, as

well as reduce the costs of exclusion in the long term;

- implement staff/provider training on communicating with refugees with disabilities in a respectful manner and understanding and appreciating the SRH rights of refugees with disabilities;
- prioritize outreach to refugees with disabilities who are isolated in their homes – especially to those with intellectual impairments – to better address their needs and to increase their access to up-to-date and accurate SRH information and services;
- include adolescents with disabilities in existing adolescent SRH activities, especially to convey critical SRH information around acceptable touching and protection strategies for adolescents with intellectual impairments;
- reduce wait times for health services through reasonable accommodation for persons with disabilities;
- address security risks for refugees with disabilities, especially protection concerns related to sexual violence, abuse or exploitation, and provide information on the benefits of seeking medical care after experiencing sexual violence and where to access services;
- apply the Inter-agency Standing Committee *Guidelines on Gender-Based Violence Interventions in Humanitarian Settings* to refugees with disabilities;<sup>15</sup>
- increase opportunities for income generation, vocational training, leadership skills, disability rights knowledge, sexuality education, peer interaction and other learning opportunities for refugees with disabilities and their caregivers, to foster independence, development, empowerment and longer-term SRH capacities;
- offer opportunities for parents and caregivers to learn about positive parenting, disability, SRH rights and gender;
- prioritize persons with disabilities and their families for resettlement assessment according to their level of risk of protection concerns in the refugee community;
- disaggregate data by disability, sex and age, to reflect accessibility of services and activities; and
- develop partnerships with DPOs and disability-focused organizations to gain from their expertise, build bridges and facilitate stronger referral and support networks.

## Organizations of Persons with Disabilities (DPOs) and Disability-focused Organizations should:

- offer their technical expertise to agencies servicing refugees on how their providers and staff can better communicate with, and foster inclusion of, persons with different types of impairments, so that refugees with disabilities can feel more respected and valued;
- engage in formal interactions and strengthen referrals with groups that have expertise in SRH service provision, to advocate for accessible and more equitable services for refugees with disabilities; and
- advocate for refugee inclusion in national disability inclusion efforts.

## Next steps

Partners to the project are implementing site-specific recommendations to improve disability inclusion in existing SRH services for refugees in their respective settings. Country-specific reports are available for each site, in addition to participants' reports in the languages in which the study was implemented. The WRC and co-investigators are further developing an article to contribute to the peer-reviewed literature and advocating around the needs, risks and capacities identified in this project.

The Consortium is developing a series of articles to contribute to the peer-reviewed literature. In the meantime, partners are attempting to operationalize findings by securing funds to pilot strategies that address identified needs in the respective settings. The research to action model aims for programs to improve the wellness and healthy development of adolescents during and following conflict.

## Notes:

1. UNHCR. 2014. *War's Human Costs: UNHCR Global Trends 2013*. [https://s3.amazonaws.com/unhcrsharedmedia/2013-global-trends/Global\\_Trends\\_report\\_2013\\_V07\\_web\\_embargo\\_2014-06-20.pdf](https://s3.amazonaws.com/unhcrsharedmedia/2013-global-trends/Global_Trends_report_2013_V07_web_embargo_2014-06-20.pdf)
2. IDMC. 2014. *Global Estimates 2014: People displaced by disasters*. [www.internal-displacement.org/assets/publications/2014/201409-global-estimates2.pdf](http://www.internal-displacement.org/assets/publications/2014/201409-global-estimates2.pdf)
3. WHO. 2011. *World Report on Disability*. [www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html)
4. Stephanie Ortoleva and Hope Lewis. *Forgotten Sisters – A Report on Violence against Women with Disabilities: An Overview of Its Nature, Scope, Causes and Consequences*, Northeastern University School of Law Research Paper No. 104-2012. <http://uscd.org/index.cfm/news/forgotten-sisters-a-report-on-violence-against-women-with-disabilities-an-overview-of-its-nature-scope-causes-and-consequence>

5. Lena Morgon Banks and Sarah Polack. 2014. *The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities. Evidence from Low and Middle Income Countries*, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine. <http://disabilitycentre.lshtm.ac.uk/files/2014/07/Costs-of-Exclusion-and-Gains-of-Inclusion-Report.pdf>
6. UN General Assembly, 67th Session, Report of the Special Rapporteur on violence against women, its causes and consequences, A/67/227, August 3, 2012, <http://www.ohchr.org/Documents/Issues/Women/A.67.227.pdf>, last accessed November 2, 2012.
7. Human Rights Council, 20th Session, Thematic study of the issue of violence against women and girls with disabilities, A/HRC/20/5, March 30, 2012, [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-5\\_en.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-5_en.pdf), last accessed November 2, 2012.
8. IAWG on RH in Crises. 2010. *Inter-agency Field Manual on Reproductive Health in Humanitarian Settings*. <http://iawg.net/resources2013/tools-and-guidelines/field-manual/>
9. UN. 2006. Article 1, Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/convention/conventionfull.shtml>
10. Environmental barriers include physical and communications-related barriers; attitudinal barriers include individual, family, community, service provider and policy-maker attitudes; and structural barriers include policy and resource-related barriers.
11. More specifically, SRH addresses access to health care that helps women have safe pregnancies and deliveries; access for couples and individuals to safe, effective, affordable and acceptable methods of family planning; access for adults and adolescents to information and services on how to prevent and care for STIs, including HIV; and access to services for survivors of sexual violence. ICPD. 1994. Programme of Action. A/CONF.171/13/Rev.1 -- Report of the International Conference on Population and Development. <http://www.un.org/popin/icpd/conference/offeng/addproga.html>
12. Maps where participants identified and labeled reproductive organs.
13. Walking through the journey of a person's life, in order to identify events, behaviors and attitudes that are relevant to SRH.
14. Activities where participants sort and organize information into categories.
15. IASC. 2005. *Guidelines on Gender-Based Violence Interventions in Humanitarian Settings*. [http://www.humanitarianinfo.org/iasc/pageloader.aspx?page=content-subsidi-tf\\_gender-gbv](http://www.humanitarianinfo.org/iasc/pageloader.aspx?page=content-subsidi-tf_gender-gbv)

## The Consortium



The Women's Refugee Commission (WRC) is an NGO based in the U.S. It is a research and advocacy organization that works to protect the rights, safety and well-being of displaced women, children and youth around the world. [www.womensrefugeecommission.org](http://www.womensrefugeecommission.org).



The Association of Medical Doctors of Asia-Nepal (AMDA Nepal) provides health services in Nepal in partnership with national and international organizations. [www.amda.org.np](http://www.amda.org.np).



The International Rescue Committee (IRC) provides services to persons affected by humanitarian emergencies around the world. In Kakuma Refugee Camp, the IRC provides health, nutrition, HIV and protection services, and supports human rights, refugee rights and equal access to services. [www.rescue.org](http://www.rescue.org).



Refugee Law Project (RLP) is a community outreach project of the School of Law, Makerere University, Uganda. It works towards empowering forced migrants and host communities to enjoy their human rights and lead dignified lives. [www.refugeelawproject.org](http://www.refugeelawproject.org).

The study in Nepal was also co-hosted by the United Nations High Commissioner for Refugees (UNHCR), in partnership with the Nepal Disabled Women Association (NDWA), the National Federation of the Disabled Nepal (NFDN) and the Damak Disability Helping Committee (DDHC). NDWA is a self-help organization led by women with disabilities that supports other women with disabilities through promoting health, education, representation and participation, economic empowerment/livelihoods, capacity building, rehabilitation services and prevention and response to GBV. NFDN is an umbrella organization of DPOs established to protect and promote the rights of persons with disabilities in Nepal through enhancing their participation in decision-making processes. DDHC promotes the status of persons with disabilities in Jhapa District in Nepal.

Full project reports, reports for participants and more information on members of the local advisory groups are available from the WRC website, [www.womensrefugeecommission.org](http://www.womensrefugeecommission.org).