



## **“We have a right to love”**

The Intersection of Sexual and Reproductive Health and Disability for Urban Refugees in Kampala, Uganda



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## Research. Rethink. Resolve.

The Women's Refugee Commission works to improve the lives and protect the rights of women, children and youth displaced by conflict and crisis. We research their needs, identify solutions and advocate for programs and policies to strengthen their resilience and drive change in humanitarian practice.

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 through research; provision of legal aid; mental health and psychosocial services; sexual violence prevention; and conflict, governance and transitional justice monitoring.

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Photographs © Apio Molly and Yusrah Nagujja, RLP. Cover photo: data collectors at work.

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## Acronyms & Abbreviations

ACTV	African Centre for Treatment and Rehabilitation of Torture Victims
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Organization of Persons with Disabilities
DRC	Democratic Republic of Congo
GBV	Gender-based violence
IAWG	Inter-agency Working Group on Reproductive Health in Crises
ICPD	International Conference on Population and Development
IEC	Information, education and communication
JRS	Jesuit Refugee Service
KCCA	Kampala City Council Authority
LAPD	Legal Aid for Persons with Disabilities
LPU	Little People of Uganda
MHU	Mental Health Uganda
NABDU	National Association of the Deafblind in Uganda
NGO	Nongovernmental Organization
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities in Uganda
OPM	Office of the Prime Minister
PWD	Person with a disability
RLP	Refugee Law Project
SGBV	Sexual and gender-based violence
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TBA	Traditional birth attendant
UAA	Uganda Albinos Association
UDEWO	United Deaf Women's Organization
UNAPD	Uganda National Action on Physical Disability
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
VCT	Voluntary Counseling and Testing for HIV
WHO	World Health Organization
WRA	Women of reproductive age
WRC	Women's Refugee Commission



## Executive Summary

Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) states that persons with disabilities should have the same range, quality and standard of free or affordable health care, including in the area of sexual and reproductive health (SRH), as provided to other persons. Yet, the needs of crisis-affected populations with disabilities are notably absent from global SRH and gender guidelines and standards for humanitarian practice.

To address this gap, the Women's Refugee Commission (WRC), the Refugee Law Project (RLP) and other stakeholders undertook a qualitative examination of the specific risks, needs and barriers for Congolese and other refugees with disabilities to accessing SRH services in Kampala, Uganda, as well as their capacities and practical ways to overcome these challenges. The target population of refugees was those with long-term physical, intellectual, sensory and mental impairments who experience barriers in society that hinder their full and effective participation on an equal basis with others. This group included women with disabilities aged 20-49 years; men with disabilities aged 20-59 years; and adolescent girls and boys with disabilities aged 15-19 years. Caregivers and family members who cared for adolescent or adult refugees with disabilities were also consulted for this study.

Participatory methods, based on a literature review and consultative processes, were applied for this study. Participatory activities among refugees with disabilities included: mapping, sorting and developing timelines to explore knowledge of the reproductive system and fertility; examining community perceptions surrounding persons with disabilities and their SRH; and reviewing barriers to accessing information and services; perceptions around different types of treatment; and determining risk and protective factors. Activities among family/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. Refugees and persons with disabilities were recruited as part of the study team to utilize their skills and capacities and facilitate empowerment processes.

This study among refugees with a variety of disabilities in Kampala is one of three studies exploring the intersections between SRH and disability in humanitarian settings. In the Kampala study, a total of 103 refugees with disabilities participated in the study, of whom 74 were women and girls, and 29 were men and boys. Thirty-three caregivers and family members of refugees with disabilities were also consulted. Participants were consulted in Swahili, Somali, Kinyarwanda and Luganda sign.

### Key Findings

- **Overarching concerns:** Overall, most refugees with disabilities felt they are looked down upon because of their disability. Resettlement was refugees with disabilities' and caregivers' overwhelming request to address their prevailing circumstances. Persons with mental disabilities<sup>1</sup> often reported acquiring impairments after experiencing conflict-related trauma prior to their current displacement, some of which reflected SRH concerns, including early and forced marriage.
- **Awareness of SRH concepts and services:** Many participants were aware of which agencies provided SRH services, although knowledge of SRH was mixed. Adolescents generally knew less than adults. Group activity participants—irrespective of sex, language and type of disability—were generally aware of HIV or some symptoms of sexually transmitted infections (STIs), as well as at least one family planning method. However, mistrust and misconceptions of family planning were common. Refugees who were unable to leave their home and/or had multiple impairments were less aware about SRH due to their limited mobility and opportunities to receive

information. Findings also revealed the need to provide SRH information and guidance on relationships to adolescents, and even to parents with disabilities who missed opportunities to receive such information themselves to convey to their children.

- **Experiences around use of health and SRH services:** The lack of translation (including local sign language), lack of transport and lack of money to pay health providers were seen as barriers to accessing health care. Many refugees with disabilities perceived health services to be inadequate in terms of the wait times and quality of care, and mistreatment from staff was a major stigmatizing factor. Being a refugee and having a disability reportedly created a double burden for refugees across all languages.
- **Experiences of women or girls with disabilities who become pregnant:** Both adult and adolescent participants agreed that treatment of a pregnant woman or girl with disabilities by family and community members would be based on her marital status, while economic circumstances would influence treatment by health providers. If the pregnant woman or girl with disabilities is unmarried, she may be seen as a prostitute, as having misbehaved, or as having been raped. No one mentioned that she may be in a consensual, romantic relationship. Several groups across sex, age and language mentioned that the woman's or girl's parents would force her to have an abortion or marry the responsible man or adolescent boy. Participants reported that health care workers, at times, poorly treated a pregnant woman or girl with disabilities because of her refugee status and disability.
- **Autonomy of refugees with disabilities in their ability to exercise SRH rights:** Group participants mentioned the possibility of forced abortion for women and girls with disabilities

who had unwanted pregnancies. The ability of a man or adolescent boy with disabilities to impregnate a woman or girl was seen as more acceptable by most groups of refugees with disabilities than the ability of a woman or girl with disabilities to become pregnant. Little was mentioned regarding the ability of refugees with disabilities to exercise their SRH rights, although many refugees with disabilities agreed that they should be able to engage in romantic relationships. Women with disabilities who are isolated in their home appear to have less stable relationships and are subsequently raising children without a partner. They are often blamed by family members for increasing caregiver responsibilities in the household, raising concerns about abuse and exploitation in and outside of the family.

- **Perceptions around treatment of refugees with disabilities:** Even refugees with disabilities themselves reported that it was acceptable for caregivers to control the money of a person with disabilities depending on the type of impairment. Some groups of adults with physical impairments further condoned forced sterilization, especially for persons with intellectual impairments, which reflected social prejudices, even among refugees with disabilities. The majority felt refugees with disabilities should be leaders and have equal opportunities for relationships, education and participation.
- **Safety concerns and risk of sexual violence:** Most groups associated safety with physical accessibility rather than personal safety. However, the toilets, neighborhood, water collection points and an empty home were seen as unsafe locations; the former two especially for risks of sexual violence. Several women with disabilities disclosed incidents of past sexual violence, including some that led to unwanted pregnancy. No recent incidents, including among adolescents or young

children, were shared, although risk factors for sexual violence were major concerns for caregivers in particular. A handful of refugees with disabilities—including some with mental disabilities—were aware of post-rape care and the benefits of seeking care.

- **Coping strategies, protective and facilitating factors:** Persons with mental disabilities in particular reported RLP's counselors as safe persons. For refugees who were unable to leave their homes, family members—especially mothers—were reported as safe resources. Several caregivers felt schools—when safe—were a protective space for their children with disabilities, as interactions with other children and the acquisition of communication skills improved their home situation.
- **Recommendations from refugees with disabilities and caregivers:** Recommendations offered by refugees with disabilities to improve their SRH experience often reflected improvements in quality of care, as well as activities to empower themselves. Suggestions included training service providers on how to work and communicate respectfully with refugees with disabilities; employing sign language and other language interpreters in health facilities; managing referrals better among agencies; and providing vocational training, English language classes and educational opportunities for refugees with disabilities and caregivers to become self-sufficient.

## Key Recommendations

**Donors and governments supporting agencies servicing refugees** should:

- Facilitate disability-inclusion among agencies they support by providing funds for staff/provider learning and training opportunities; creating incentives to develop programming partnerships with agencies that have disability programming expertise; and facilitat-

ating increased national, regional and global dialogue on improved 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, language classes and other learning opportunities.
- 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 to meeting the needs of the clientele with disabilities, as well as reduce the costs of exclusion in the long term.
- Implement awareness-raising and staff/provider trainings 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 who can be hidden—to increase their access to up-to-date and accurate SRH information and services.
- Reduce wait times for refugees with disabilities through reasonable accommodation for persons with disabilities.
- Address security risks for refugees with disabilities, especially protection concerns related to sexual violence, abuse or exploitation, particularly for those raising children on their own.

- Expand referral networks and increase opportunities for income generation, vocational training, language classes, leadership skills, disability rights knowledge and other learning opportunities for refugees with disabilities and their caregivers, in order to foster their independence, development, empowerment and longer-term SRH capacities.
- Offer opportunities for parents and caregivers to learn about positive parenting, disability, SRH rights and gender.
- Continue to support existing networks of refugees with disabilities for them to help themselves and build on each other's strengths, such as language skills.
- Disaggregate data by disability type, in addition to sex and age.
- Develop partnerships with organizations of

persons with disabilities and disability-focused organizations to gain from their expertise in working with persons with disabilities, 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 persons with different types of impairments, so that refugees with disabilities can feel more respected and valued when they seek services.
- Engage in formal interactions and strengthen referral networks with groups that have expertise in SRH service provision, to advocate for accessible and more equitable services for refugees with disabilities.



Data collectors practicing the body mapping exercise.



## I. Introduction

In 2012, 45.2 million people were forcibly displaced by conflict and persecution,<sup>2</sup> and 32.4 million were displaced by a natural disaster.<sup>3</sup> Persons with disabilities, defined under the Convention on the Rights of Persons with Disabilities (CRPD) 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>4</sup> are estimated by the World Health Organization (WHO) to make up 15 percent of the global population,<sup>5</sup> a figure that is likely to be higher in situations of humanitarian crisis. The estimate of persons with disabilities in stable contexts is often an underestimate; thus, it can be expected that the estimates in humanitarian contexts are even harder to calculate. A 2013 HelpAge International and Handicap International survey of Syrian refugees in Jordan and Lebanon, for example, found that 22 percent of surveyed refugees live with an impairment.<sup>6</sup>

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>7</sup> They may have less access to SRH information, which promotes healthy and safe relationships, protects them from HIV and other sexually transmitted infections (STIs), and enables autonomy in family planning decisions. The costs of exclusion can lead to poorer health outcomes and inefficient spending—for example, studies show that treatment for HIV in low- and middle-income countries amounts to US\$8,900 per person over the life-course, in contrast to an estimated US\$11 to prevent one case of HIV. The cost of exclusion is tremendous, especially when compounded by other social and economic costs.<sup>8</sup> Many individuals have been subjected to forced sterilizations, abortions and marriages because of ingrained stigmatization.<sup>9</sup> Recent reports to both the Human Rights Council and the United Nations (UN) General Assembly highlight the multiple and intersecting forms of discrimination that are experienced by women with disabilities and increase their vulnerability to many different forms of violence,

including gender-based violence (GBV).<sup>10</sup>

In 2008, the Women’s Refugee Commission (WRC) embarked on cross-sectional research that examined the protection concerns of persons with disabilities in humanitarian settings, releasing a report and a toolkit for practitioners. In Nepal, Thailand and Ecuador, the field studies cited sexual violence, domestic abuse and physical assault as protection risks facing refugee women with disabilities.<sup>11</sup> More recent assessments conducted by the WRC with refugees and displaced persons in Bangladesh, Ethiopia, India (New Delhi), Lebanon, Nepal, Philippines (Mindanao), Thailand and Uganda found that violence was reported by both men and women with disabilities in all contexts. Women and girls with disabilities were most likely to report concerns about sexual violence, with concrete examples suggesting that those with intellectual and mental disabilities may be most at risk. Isolation, lack of contact with community networks and few independent living options also exposed both men and women with disabilities to different forms of violence inside the home. Further, adolescents and young persons with disabilities were excluded from peer activities that could facilitate the development of vital social networks and enhance their protection from various forms of violence, including GBV.<sup>12</sup> Other field assessments in Ethiopia have also identified that caregivers of adolescent girls with disabilities face challenges in maintaining privacy and dignity when supporting personal hygiene and menstruation.<sup>13</sup> There is, however, a lack of information about the wider SRH needs and capacities of persons with disabilities in humanitarian contexts.

Additionally, Article 25 (a) of the CRPD articulates 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 SRH and population-based public health programs.<sup>14</sup> However, the needs of women, girls, men and boys with disabilities are notably absent from global SRH and gender guidance, and from humanitarian standards for practice. 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 currently address issues of equitable SRH access for women, girls, boys and men with disabilities, or the specific SRH vulnerabilities and risks faced by this particular group.<sup>15</sup>

The WRC therefore undertook a project to explore the intersections between SRH and disabilities in three humanitarian settings in Kenya, Nepal and Uganda. This report focuses on the experience of adults and adolescents with disabilities in Kampala, Uganda. The study was undertaken in partnership with Refugee Law Project (RLP).

## II. Objectives

The overall objective of the study was to acquire information on the SRH needs, vulnerabilities and capacities of refugees with disabilities. The study question explored: What are the specific risks, needs and barriers for persons with disabilities to access SRH services in humanitarian settings, and what are the capacities and practical ways that the challenges can be addressed?

As per the CRPD, “persons with disabilities” were 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>16</sup>

“Barriers” were defined as environmental, attitudinal or structural barriers. 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.

The term “disability” is used throughout this report to reflect the interaction between these different factors—impairments and barriers—as described in the preamble of the CRPD.<sup>17</sup> This definition is also aligned with the social model of disability that identifies that discrimination of persons with disabilities occurs, “not because of an impairment, but as a result of limitations

imposed by the particular context in which people live.”<sup>18</sup> Hence, humanitarian actors can identify and remove these “disabling” barriers to access and inclusion in their programs.

“Sexual and reproductive health” was defined by the International Conference on Population and Development (ICPD) to include safe motherhood (maternal newborn health), family planning, STIs including HIV, and GBV.<sup>19</sup> 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.

Sub-study questions include:

- What are the specific SRH needs and risks faced by refugees with disabilities in humanitarian settings?
- What are the barriers (environmental, attitudinal and structural) and challenges for refugees with disabilities to accessing existing SRH services?
- What is the impact of stigma and caregiver/family/provider attitudes on access to SRH services for refugees with disabilities?
- What communications strategies (including messaging, means, materials and others) are being employed to reach refugees with disabilities?
- What systems are in place to protect refugees with disabilities from SRH risk?
- What are the perspectives of refugees with disabilities of these SRH services?
- What capacities and strategies have refugees with disabilities employed to meet their SRH needs and protect them from SRH risks?
- What additional facilitating factors can help refugees with disabilities meet their SRH needs and protect them from SRH risks?

## III. Uganda Context

### SRH of persons with disabilities in Uganda

The Government of Uganda adopted the Persons with Disabilities Act in 2006 and became a state party to the CRPD in 2008. The Disabled Persons Act stipulates that provision of services for persons with disabilities should be equal to those of persons without disabilities. However, many reports indicate that persons with disabilities still face difficulty in accessing basic services such as education, employment and health care.<sup>20</sup> The National Union of Disabled Persons of Uganda (NUDIPU), an umbrella network of organizations of persons with disabilities (DPOs), coordinates the work of 24 DPOs that advocate for the rights of persons with disabilities in Uganda and their access to programs and services.

Existing research from both the conflict-affected north and other areas of Uganda show the vulnerabilities of persons with disabilities to GBV in particular, and factors that impede access to SRH information and services. A 2010 National Union of Women with Disabilities Uganda (NUWODU) survey of women with disabilities in northern Uganda found that women and girls with psychosocial and intellectual impairments were highly vulnerable to GBV due to their inability to resist sexual violence, communicate and report perpetrators. Twenty-one percent of female respondents with disabilities reported having experienced some form of GBV; the most common form being rape.<sup>21</sup> Similarly, a 2010 study by Human Rights Watch that interviewed 64 women and girls with disabilities in northern Uganda found that over a third had experienced some form of GBV, including rape. Women with disabilities were reportedly vulnerable to GBV because of social exclusion, limited mobility and lack of support structures. Discriminatory attitudes were also a major barrier to the full inclusion of women with disabilities.<sup>22</sup>

Additional studies examining the SRH situation for persons with disabilities in other areas of Uganda include Access for Action Uganda's 2009 study among persons with disabilities, nongovernmental organization (NGO) staff and health care providers that found that the majority of persons with disabilities often lack access to basic

information about SRH. Researchers found that persons with disabilities, depending on the degree and nature of their impairment, were often denied the right to establish relationships or were forced into unwanted marriages.<sup>23</sup> A 2003 study of SRH and HIV/AIDS among persons with disabilities in three districts found that poverty, stigma and discrimination, provider attitudes, lack of confidentiality and geographical inaccessibility of health facilities were major problems faced by persons with disabilities, as well as exclusion from SRH sensitization and awareness-raising programs. SRH challenges faced by women with disabilities included sexual exploitation, unwanted pregnancy and complications during childbirth.<sup>24</sup>

### Displacement in Kampala

Kampala is host to more than 82,000 refugees.<sup>25</sup> Refugees have arrived in several different ways: via the agricultural settlements in rural Uganda, directly to Kampala from their country of origin or via transit countries such as Kenya. Most have fled conflict, some arriving in earlier decades, and others coming from more recent conflicts in Rwanda, Burundi, the Democratic Republic of Congo (DRC), South Sudan, Somalia, Ethiopia and Eritrea. Refugees are scattered across the city's slums, with Somalis concentrated in the central neighborhood of Kisenyi and the Congolese in Katwe, Makindye and Masajja. Urban refugees reportedly face many of the same barriers as the Ugandan poor in accessing services, finding employment and staying safe.<sup>26</sup> However, past research has found that they also face additional constraints, such as language, discrimination, lack of legal documentation and limited access to credit and formal sector employment.<sup>27</sup>

### Situation for refugees with disabilities in Kampala

According to the UN High Commissioner for Refugees (UNHCR), as of June 2013, there were 452 refugees with disabilities registered with the agency in Kampala. This is much less than the 15 percent of the refugee population expected from global estimates, and may be the result of gaps in identifying persons with disabilities and/or recording this information accurately in current databases. UNHCR does, however, disaggregate this

data by the following categories: persons with hearing impairments, including deafness (46); persons with intellectual impairments (70); persons with physical impairments (167); persons with speech impairments (12); persons with visual impairments, including blindness (126); and persons with other impairments (31). A separate category for mental/psychosocial impairments was not available. Roughly 73 percent were persons between ages 18 and 59.<sup>28</sup> If the conservative estimate of 15 percent of the population having a disability is applied, 6,900 refugees with disabilities are expected out of the total registered 46,000. More recently in 2014, 725 refugees with disabilities (415 female and 310 male) have been registered with UNHCR; the majority who have been serviced by InterAid.

Several agencies provide services to refugees with disabilities in Uganda. RLP provides counseling, social services, income generation, advocacy, coordination and capacity-building through skills training. RLP has installed screen-reader software for persons with vision impairments in its resource center and has piloted the Global Disability Rights Library,<sup>29</sup> providing refugees with disabilities, their families and many others with access to resources on disability rights. UNHCR's urban implementing partner in Kampala, InterAid, promotes the participation of and provides counseling, capacity building, skills training, livelihoods support, education support and primary health care—inclusive of SRH services—to families with refugees with disabilities. Additionally, InterAid networks with institutions that support persons with disabilities. UNHCR Uganda, in implementing the UNHCR Sexual and Gender-based Violence (SGBV) Updated Strategy (June 2011), trained staff on the six action areas, including “Protecting Persons with disability against SGBV,” and has evaluated its progress.

Mulago Referral Hospital provides rehabilitation services, including through the provision of aids and devices, and receives referrals from InterAid and other health organizations. UNHCR supports special education for select refugee children with disabilities and provides livelihood opportunities to families with persons with disabilities. It has further accelerated rollout of UNHCR's global *Guidance on Working with Persons with Disabilities*

*in Forced Displacement*<sup>30</sup> through trainings and other initiatives. Such agencies are increasingly developing partnerships with DPOs to benefit from their technical expertise and specialized programs.<sup>31</sup>

UNHCR and the Office of the Prime Minister (OPM) have expressed concerns about refugees with disabilities leaving the refugee settlements and coming to Kampala, due to the perception that they will add more demand to the already constrained resources available for supporting refugees in Kampala.<sup>32</sup> However, UNHCR notes that urban policy is such that all refugees should be informed of services in the settlement, as well as in urban areas.

Refugees with disabilities have themselves come together to form their own support groups. Supported by the RLP, the Association for Refugees with Disabilities in Uganda was established in 2011 and provides support to roughly 121 families in Kampala.<sup>33</sup> Through a growing network of refugee families, the Association has been able to identify new arrivals and share information about available services and assistance, including agencies that have dedicated disability officers and focal points. Representatives have further been identified for the various national origins and languages that are used by the diverse refugee community. InterAid additionally facilitates the formation of groups for social support.

### SRH and refugees with disabilities in Kampala

In a review of literature in mid-2012, no research was found that explored SRH issues among refugees with disabilities living in Kampala, although newer assessments have examined the broader health needs of persons with disabilities in Syria and other humanitarian settings.<sup>34</sup> Consultative meetings with DPOs in Kampala revealed that, due to the challenge of transportation, refugees with disabilities in Kampala often fail to access public services, including hospitals and schools. Health care personnel are often not adequately trained to work with refugees with disabilities.<sup>35</sup> For refugee girls with disabilities who experience sexual exploitation and abuse; it is often only when they become pregnant that the abuse is recognized.<sup>36</sup>



## IV. Methodology

An important consideration for the WRC was to ensure maximum participation and input from various stakeholders in the design and implementation of the SRH and disability study. As such, the WRC convened meetings with DPOs and other stakeholders in Kampala in 2012, to collectively develop the participatory research methodology in advance of the field assessments and select a local co-investigator (RLP). A major outcome was the establishment of an advisory group comprising DPOs, NGOs and representatives of refugees with disabilities. The Uganda advisory group is one arm of the global advisory group for the WRC's wider project that also includes representatives from Kenya and Nepal. Collectively, the advisory groups informed the development of the study design and instruments. The study was approved for implementation in Kampala by the Uganda National Council for Science and Technology.

### IV.i. Study participants

The target populations selected for this study are:

- Refugees who self-identified as person with disabilities and had been displaced or crisis-affected. This included persons with **physical, intellectual, sensory and mental impairments** among 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)
- Caregivers/family members who care for adolescent or adult refugees with disabilities

Refugees with disabilities for inclusion in this study represented those who self-identified with the CRPD

definition of persons with disabilities. Additional guidance was given to the study team to ensure that members were aware of the variety of impairments encompassed in the CRPD definition and invited such persons to participate in the study:<sup>37</sup>

- Persons with long-term difficulty moving, walking or climbing steps (physical impairments).
- Persons with long-term difficulty seeing, even if wearing glasses (vision impairments).
- Persons with long-term difficulty hearing, even if using a hearing aid (hearing impairments).
- Persons with a mental health condition that alters their thinking, mood or behavior, and is associated with distress or interference with personal functions (mental impairments).
- Persons who have difficulty understanding, learning and remembering new things, and in applying learning to new situations (intellectual impairments).
- Persons who have multiple impairments and/or severe functional limitations, often unable to leave their homes and may need assistance with all personal care.

While women and men are often sexually active after age 49, the primary focus of the adults with disabilities groups was up to 49 years for women and 59 years for men, similar to the cut-offs of the global Demographic and Health Surveys.<sup>38</sup> The age cut-off between adult and adolescent groups was 19, taking into account WHO's definition of adolescents as 10-19 years of age.<sup>39</sup> Among caregivers and family members, priority was given to those who were caring for adolescents or adults with disabilities. Refugees with disabilities who were not able to demonstrate consent or assent, or adolescents for whom parental consent could not be obtained were excluded from this study for ethical considerations (see informed consent section below for more information). The former included refugees with disabilities with more profound psychosocial and intellectual impairments, although in many cases, their caregivers were interviewed for their experiences and perspectives.

#### IV.ii. Participatory activities

The study used qualitative, participatory methods to enable a cross-sectional examination of the specific risks, needs and barriers for refugees with disabilities to accessing SRH services, and the capacities and practical ways that the challenges could be addressed. Based on a literature review and the consultative process with the study's advisory groups, the selected participatory activities included body mapping,<sup>40</sup> timelines<sup>41</sup> and sorting<sup>42</sup> to explore knowledge of the reproductive system and fertility; community perceptions surrounding refugees with disabilities and their SRH; barriers to accessing information and services; perceptions around different types of treatment; and risk and protective factors.<sup>43</sup> To gauge how refugees with disabilities perceived various treatment towards persons with disabilities, 28 cards were developed with pictorial scenarios and accompanying text, for participants to sort into categories of "acceptable," "unacceptable" or mixed treatment. In order to determine safe and unsafe spaces, 24 photographs of the community were taken for participants to sort as to whether the locations or persons were seen as safe, unsafe or both. In keeping with existing guidelines and recommendations on disability inclusion,<sup>44</sup> activities were adapted with visual aids, simple language and other modifications to enable maximum participation from refugees with different impairments.

Activities with family/caregivers were intended to spur discussion regarding new experiences and concerns that emerged as a result of the child/family member maturing into a teenager or an adult, and experiences seeking health care for their child/family member with a disability.

#### IV.iii. Sampling and segmentation

The overall study design employed a maximum variation approach seeking to include different populations of refugees with disabilities in Kampala. Participants were stratified into four groups based largely on communication methods, in addition to segmentation by age, sex and language (four languages, including Luganda sign). These were:

- Group activity

1. Refugees with physical, vision and mild mental (psychosocial) impairments
  2. Refugees with hearing impairments
  3. Refugees with mild intellectual impairments
- Individual interview
  - 4. Refugees with other needs and impairments that required more individualized communication approaches (those unable to leave their home; those with multiple impairments; new mothers; etc.)
  - Caregiver/family member focus group discussion

The groups were fluid and were divided by participants' ability to **functionally communicate** with other participants and the facilitator. The aim was to secure wide representation and participation. Those in the "refugees with physical, vision and mental impairment" group also included other refugees with disabilities who could use similar means of communication.

RLP's existing records of impairment type and lists from the Association for Refugees with Disabilities in Uganda were referenced to identify participants with a diversity of impairments. No official assessment was undertaken to verify or "diagnose" the impairment and participants were invited to self-identify their disability. The priority was to ensure participants could communicate and participate with the accommodations made for the particular group. In groups where varying impairments were represented, the facilitators were trained to probe within each group about any differences between the types of impairments they represented.

Smaller group activities were convened for refugees with mild intellectual impairments to ensure the sessions were facilitated well enough for everyone to participate. Individual interactions were used for persons with multiple disabilities, new mothers and other persons for whom in-depth activities at a person's home were more appropriate than a group environment.

Different study instruments were used for group and

individual activities, which were field tested in Swahili and Somali prior to the activities to ensure acceptability and validity. Among caregivers/family members, the same interview guide that was used for focus group discussions was used as an interview guide for caregivers of persons with disabilities who were unable to leave their homes.

Participants were identified through convenience sampling methods. Standard approaches to qualitative research for focus group size (6-12) and number were applied where feasible.<sup>45</sup> In total, 103 refugees with disabilities participated in the study, of whom 74 were women and girls and 29 were men and boys. Thirty-three caregivers and family members of refugees with disabilities were also consulted. The activities were conducted in Swahili, Somali, Kinyarwanda and Luganda sign; Swahili was selected as the dominant language, given the number of Swahili-speaking refugees in Uganda. While initially more sign groups were

arranged, participant recruitment activities showed that younger children were better able to sign in a common language (Luganda) as a result of educational opportunities afforded to them in Luganda sign. Most refugees of reproductive age used their own modes of sign with their caregivers; hence, several group activities were dropped. Table 1 below shows the numbers of participants ultimately consulted.

#### IV.iv. Participant recruitment

Swahili- and Kinyarwanda-speaking refugees with disabilities and Luganda-signing refugees with disabilities were recruited through contact lists managed by RLP and the Association for Refugees with Disabilities in Uganda, as well as snowball sampling from identified contacts. RLP runs a mental health program for refugees, which enabled easy identification of refugees with mental disabilities in particular. The Somali

Table 1: Number of participants consulted in Kampala					
Kenya	Total	1. Refugees with physical, vision and mild mental (psychosocial) impairments	2. Refugees with hearing impairments	3. Refugees with mild intellectual impairments	4. Other refugees (who are unable to leave home, have multiple impairments, new mothers, etc.)
Women of reproductive age (20-49 years)	50	Swahili: 13* Somali: 8 Kinyarwanda: 10	Luganda sign: 3	Swahili: 8*** Somali: 5	Swahili: 1 Somali: 1 Kinyarwanda: 1
Men (20-59 years)	17	Swahili: 12*	0	Swahili: 5	N/A
Adolescent girls (15-19 years)	24	Swahili: 5 Somali: 3 Kinyarwanda: 11**	0	Swahili: 2	Swahili: 1 Somali: 1 Kinyarwanda: 1
Adolescent boys (15-19 years)	12	Swahili: 8	0	Swahili: 4	N/A
Caregivers/family members	33	Swahili: 18 Somali: 12			Swahili: 1 Somali: 2
<p>* One of two groups comprised only participants with mental impairments.  ** As the study did not attempt to diagnose impairments, several participants in this group may not have been persons with disabilities, but joined this group due to misunderstanding of eligibility criteria.  *** Given challenges in discerning between impairment types, this group includes several participants who may likely have mental impairments rather than intellectual impairments. Hence, this group was mixed.</p>					

community leader further helped identify refugees with disabilities from the Somali community using available household lists, although the exact impairment was often self-reported.

As part of participant recruitment, data collectors made cell phone calls to the refugees with disabilities' home and/or made home visits to explain the purpose of the study, expectations for participation and use of findings. They also clarified any questions to prevent any misunderstanding. Fact sheets written in Somali, Swahili and Kinyarwanda were disseminated at this time.

#### IV.v. Study team composition and training

WRC and RLP recruited 12 refugee data collectors and participant mobilizers, including several with physical disabilities. They participated in a three-day training on human subjects research; SRH topics; appropriate communications skills per type of impairment; facilitation and recording skills; consent/assent processes; ethical data handling; and referral pathways to existing health, protection and psychosocial services. The trained interviewers piloted the study instruments and tools (images, photos, etc.) before they engaged in actual data collection, and received frequent support and review of skills throughout data collection, particularly during daily debriefing sessions. Team members ultimately comprised facilitators, notetakers and participant mobilizers. A Luganda sign interpreter was hired to interpret for the group activity conducted in sign. Extensive effort and sensitivity were employed to ensure all participants were consulted in safe and culturally appropriate ways.

#### IV.vi. Informed consent

Informed verbal consent was sought from all refugees with disabilities in their local language and tailored to accommodate different impairments. Languages for consent included Swahili, Somali, Kinyarwanda and Luganda sign. The consent process included information on how participants were selected, the nature of the study and the types of questions they would be

asked if they consented. Participants were assured that individual names would not be collected or used in any study findings. Only those participants that consented were permitted to participate.

Those who did not have capacity to provide full informed consent (due to age or barriers in communication) were asked to provide verbal agreement, and the caregiver asked to verbally consent in advance of the activity. Per Ugandan law, minors (15-17 years) were asked to verbally assent, and a parent/guardian was asked to provide verbal permission. Pregnant girls, those who had children, or those who were married or living on their own provided their own consent.

For persons with a perceived intellectual impairment, the consent/assent process was interactive to facilitate more effective communication of information and establish their understanding of their involvement in the activities. As applied in other SRH-related studies,<sup>46</sup> once objectives and the process had been explained, a member of the study team asked the following questions:

1. What will we be talking about in the activity?
2. How long will the activity be?
3. Can you think of a reason why you might not want to participate?
4. If you do not want to answer any of the questions, what can you do?

Potential participants were required to answer questions 1 and 4 correctly, which all participants managed to do. If they had not, but still expressed interest in participating, caregiver/family member permission would have been sought during the initial home visit.

During the time of the actual activity, onsite verbal consent was obtained before any activity proceeded. This step was incorporated to ensure that participants had another opportunity to opt out if they wished. The consent process was similar to the advance consent process, although specific ground rules, such as confidentiality and how to uphold it, were discussed in depth. For activities among persons with intellectual



impairments, the facilitator asked the following interactive questions:

1. What will I be talking to you about today?
2. How long will the activity be?
3. Can you think of a reason why you might not want to talk to me?
4. If you do not want to answer any of my questions, what can you do?
5. When would I have to tell someone else what you have told me?
6. Are you still happy to take part in this study?

Potential participants were required to answer questions 1, 4 and 5 correctly, and a “yes” needed to be obtained for question 6 from every person in a group setting.

Caregivers/family members who participated in activities were asked only to provide verbal consent, per standard WRC protocol for field research in humanitarian settings.

#### IV.vii. Other ethical considerations

Individuals were informed of existing health or psychosocial services if they revealed recent experiences of violence or requested additional information and services. The referral system built on RLP’s existing network; many of the referral organizations were RLP’s existing partners.

Personal identifiers were only collected to make initial contact with potential participants for recruitment purposes. During data collection, no personal identifiers were recorded or retained from any study participant in either direct or coded form. Mappings, timelines and other posters developed during participatory exercises were photographed for translation and data analysis. RLP collected the data collectors’ handwritten notes at the end of data collection activities. Typed transcripts were made available only to WRC and RLP staff involved in the study for data analysis.

#### IV.viii. Data analysis

Preliminary data analysis began at the end of each day when the study supervisors from the WRC and RLP, facilitators, note takers and, where appropriate, the sign interpreter, convened to debrief on the day’s activities. Team members reviewed responses to each activity and question and directly translated their notes for the study supervisors and transcribers to type notes in English. RLP further facilitated a discussion among the team on their views and analysis after the last activity was conducted.

The WRC analyzed transcribed data on NVivo 10, a qualitative data analysis software, and Excel. A question-by-question approach, as well as key tags, were used to summarize participant comments into multiple themes. Photographs of the violence and treatment mappings were included to support the verbal transcripts. During the coding process, data were continuously reviewed, emerging patterns noted and relationships between constructs and themes identified. Findings were analyzed within and between activities, with comparisons made across language, sex, age and impairment group of participants.

#### IV.ix. Limitations

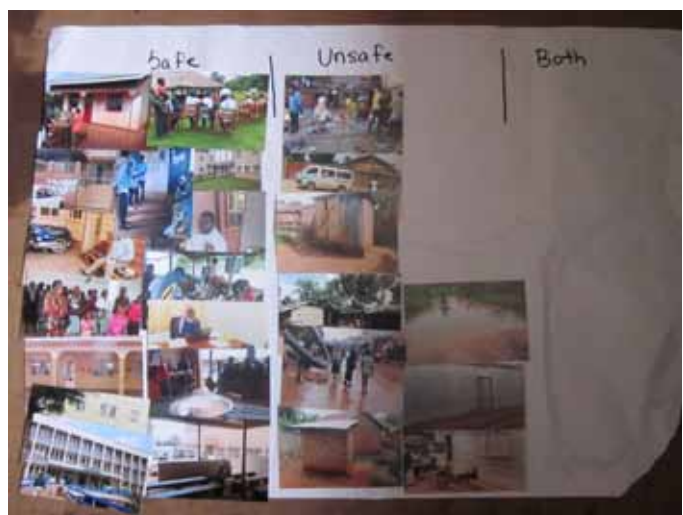
Not all impairments and ages were adequately represented in the study to draw disaggregated findings. This was particularly the case for those who used sign language to communicate, and those with intellectual or mental impairments. Most people using Luganda sign language were younger than the cut-off age of the study, as these educational opportunities have only recently become available. Data collectors found it challenging to identify persons with intellectual and mental disabilities, as a strict screening process was not employed during participant recruitment and they were often hidden from public view. Analysis thus focused on general and common findings across refugees with disabilities rather than attempting to solicit saturation by impairment group or even by ethnic origin.

Due to ethical and safety concerns, young chil-

dren were not consulted, and all participants were encouraged to share common experiences rather than personal incidents. As such, security and other concerns may be underrepresented. Participants were informed of existing services should they have wished to seek assistance.

The study heavily emphasized recruiting refugees and refugees with disabilities as data collectors in order to benefit from their local knowledge and expertise, as well as to contribute to their capacity development. As a result, some of the data collectors were acquaintances of a few of the participants, while others were RLP's direct beneficiaries. This may have impacted participant responses, especially towards social desirability bias or a pressure to respond in a certain way. The team was trained to maintain a neutral and encouraging environment to minimize possible effects.

The study employed facilitated translation techniques in which transcription was conducted immediately after the activity on the same afternoon with the facilitator, note taker and transcriber.<sup>47</sup> This minimized recall bias and translation error; however, three transcriptions were redone at a later time with the data collectors and their handwritten notes, due to their quality and questionable content. As the data were reviewed and discussed with data collectors, additional errors are unlikely; yet, the possibility of omitted information exists.



Example of the safety mapping exercise.

## V. Findings

### V.i. Overarching concerns

Findings showed that, overall, most refugees with disabilities felt they are looked down upon because of their disabilities. Comments included: "A persons with a disability is considered like someone useless in the community, such that they stop their children from associating with them"<sup>48</sup> and "It becomes worse when it comes to a person with intellectual impairments. They call them mad people."<sup>49</sup> Others noted: "Some family members will abuse you, saying you are cursed....People do not interact with you; others will not even come to your home."<sup>50</sup> Such comments prevailed across sex, language, age group and impairment category.

All participants and caregivers felt there should be more considerations for refugees with disabilities. The overwhelming request, especially from caregivers, was for them to be resettled, as many felt the care they could receive in Kampala was not enough for their family members' disability.

Both female and male participants with mental disabilities often attributed their impairment to conflict-related trauma that they experienced as a witness or a victim in their home countries. Several Swahili-speaking adult women disclosed past and even multiple incidents of rape that had occurred prior to their displacement, some of which had led to early and forced marriage where the girl's family attempted to settle the incident by having her marry the perpetrator.<sup>51</sup> Such traumatic experiences resulted in their acquiring mental disabilities.

### V.ii. Awareness of SRH concepts and services

Participants listed InterAid, Mulago Hospital (the main referral hospital), African Centre for Torture Victims (ACTV), Kampala City Council Authority (KCCA), RLP, HAIS, Red Cross, Pan African Development Education and Advocacy Programme (PADEAP) and

Jesuit Refugee Service (JRS) as organizations that provide information and services for SRH. InterAid, Mulago Hospital, ACTV and KCCA were most often mentioned. All groups across sex, impairment type and age, mentioned at least one source of information, although most listed three or more.

Despite participants noting these outlets for SRH information, awareness regarding SRH was variable. In body mapping activities where participants were asked to place cards with pictorial reproductive organs on a blank male and female human body, while several participants knew where the organs were located on the body and their functions, most were not very clear about how their bodies functioned. Overall, adolescent girls and boys tended to know less than adults. Those with intellectual impairments had more difficulty identifying and locating body parts, and were generally less aware about how they worked. Participants who were isolated in their home and/or had multiple impairments appeared to know even less about SRH.

Most group activity participants were aware of HIV and some symptoms of STIs, mentioning painful urination, vaginal discharge, abdominal pain and genital itching. However, they were not always familiar with the names of STIs or exact causes. Ebola, for example, was raised as an STI by a group of Swahili-speaking adolescent boys with physical, visual and mental impairments. Participants often mentioned unhygienic toilets as reservoirs for STIs, in addition to sexual contact. Among home-based participants, only one had apparently been informed about HIV by a health worker.

In terms of family planning, condoms were often mentioned by participants. One participant in a Swahili-speaking adolescent boy group mentioned the female condom; pills and injections were also commonly cited. A Swahili-speaking adolescent girl in a group of persons with intellectual impairments explained: "I heard about family planning and they told me that it is stopping to produce many children; I heard it from the TV and Refugee Law Project. They taught us the different types of family planning methods, such as pill plan, injector plan and condom."<sup>52</sup> Other participants

mentioned intrauterine devices (coil) and the calendar method, as well as female and male sterilization. While one to a few participants in all groups could name at least one contraceptive method to spur discussion, there was generally a lot of mistrust, as well as misconceptions, about family planning options. Many feared that condoms could get stuck inside a woman's body, cause disease or make a woman lose her fertility. One group of women with physical, visual and mental impairments further believed that emergency contraception was an abortifacient. Among participants who were unable to leave their home, only one was aware of the concept of family planning through her knowledge that pills existed to prevent pregnancy. In general, participants showed much interest to learning more about contraceptives, STIs and other SRH topics.

### V.iii. Experiences around use of health and SRH services

Despite some participants demonstrating awareness around SRH topics, which showed the positive impact of existing agency efforts, access to health services, including SRH services, presented wider challenges. While some refugees with disabilities noted that they were treated well by health providers because of their disability, the majority of participants and caregivers complained about inadequate health services and maltreatment from health care staff. Refugees with disabilities and caregivers listed the lack of translation, for both spoken and sign language; lack of transport to health facilities; limited wheelchair availability at Mulago Hospital; stock-outs of medicines; as well as lack of money to pay health providers as barriers to accessing care. Many agreed that if they did not have money, due to their refugee status and the added disadvantages linked to disability, they would be largely ignored by health providers. Some mentioned that they would wait all day to receive services: "Sometimes, we go at 7:00, and we come home at 18:00. That is tiresome when there is nothing done for us."<sup>53</sup> Most groups mentioned that, "If you are disabled, you wait, wait, wait."<sup>54</sup>

All groups expressed barriers to accessing health

services due to both their refugee status and disability. One Somali caregiver mentioned that an aid agency “takes you to Mulago and leaves you at the door. They don’t give you an interpreter to speak with them at Mulago. They don’t give you money to come back home. Sometimes, we stay at Mulago without transport, until we get help from outside. We are Somali and have physically challenged people. We are also refugees. That is why they discriminate.”<sup>55</sup>

In addition to the environmental and structural barriers, attitudinal barriers appeared to have the most negative impact. A Somali caregiver stated: “When I take the child to the officers, they chase me away. Until the time I got the picture of my child who was bleeding, that is when the doctor was convinced that my child has a problem. The health service providers think that we are pretending so that we can be resettled. That is one of the challenges and barriers.”<sup>56</sup>

Another reported: “All of the doctors have developed this attitude that whenever they see a refugee come for health services, they think that they are getting an excuse to get a visa to go abroad. They don’t take the matter seriously. One doctor told me that I want to give you a letter that writes that your child’s sickness cannot be treated here. Do you think you will remember me when you go abroad?”<sup>57</sup>

Such comments by providers were voiced by participants as being discouraging and humiliating.

Regarding SRH services, an adult male participant in a Swahili-speaking physical, vision and mental impairment group complained, “Health workers think persons with disabilities do not have a right to sex, yet they are also normal like other people.”<sup>58</sup> Access to sexuality information appeared to be even more limited for persons with intellectual impairments, with their health-seeking experiences characterized by quotes such as: “[Persons with disabilities] are under-looked and neglected by doctors and nurses”<sup>59</sup> and “[Health providers] don’t consider them like normal human beings.”<sup>60</sup>

As a result of stigma and discrimination, an adult

female participant in the Swahili-speaking physical, vision and mental impairment group explained: “The staff increase our problems. They are torturing more our problems. Because we came to our country when we are disabled, we don’t get any accommodation. We are responsible for our family. Our whole family became disabled.”<sup>61</sup> Such concerns were shared across groups, especially among refugees with disabilities who have families, and caregivers.

#### V.iv. Experiences around intimate partner relationships

Group participants undertook a timeline exercise where they were asked to map life experiences of a refugee with disabilities from childhood to adulthood as they were related to her/his SRH. In this exercise, participants treated questions around persons with disabilities having intimate partner relationships as natural. Some groups mentioned that persons with disabilities have smaller social networks than persons without disabilities, but participants said that if persons with disabilities began seeking a romantic relationship from early to mid-adolescence, they could receive information from parents, friends, teachers, aunties, neighbors, the pastor, elders or health workers. Parents and friends were frequently mentioned by adolescent participants, especially for providing advice around relationships. Only one group did not feel that they had the same opportunity as others to receive information and advice: Swahili-speaking men with intellectual impairments lamented, “People in the community look at persons with disabilities as foolish people who can’t reason, and therefore, they don’t wish to waste their time advising them. Even in many offices, service providers don’t care.”<sup>62</sup>

For persons who were isolated in their homes, mobility appeared to be further restricted by attitudes of caregivers and what information they would not likely share. As a result, one caregiver of an adolescent with an intellectual impairment shared, “No, the child sees everybody the same so she can never learn about her sexuality.”<sup>63</sup>



## V.v. Experiences of women or girls with disabilities who become pregnant

Participants generally agreed that if a girl or woman with disabilities becomes pregnant, her marital status would be the key determinant of how she would be treated by her family and neighbors. If she was married, the pregnancy would be welcome by the couple and her family. Adolescents and adults alike agreed to comments such as “If the girl is married no one will criticize the pregnancy”<sup>64</sup> and “Parents and the community would be happy; the community would not laugh or point fingers at her.”<sup>65</sup> Such attitudes were widespread across languages, sex and impairment category.

On the other hand, if the girl or woman with disabilities was not married, participants across all segmented categories agreed that she would experience serious discrimination. The family and neighbors would say she is “a prostitute,” that she had “misbehaved” or that she “was raped.” An adolescent girl in a Kinyarwanda-speaking physical, vision and mental impairment group said, “The community will call her a prostitute, because if she has a disability, they will think she was raped.”<sup>66</sup> Somali adolescent girls further agreed: “The family and friends will condemn her when they see her pregnant,”<sup>67</sup> and “The family and neighbor will think badly and even abuse and beat her for carrying an unwanted child.”<sup>68</sup> The Somalis in particular felt pregnancy out of wedlock would be problematic due to their culture, although Swahili-speaking male groups with intellectual impairments also attested to possible beatings if the girl or woman was not married. Participants in the Luganda sign group also mentioned: “She becomes a laughing stock. People would alert each other.”<sup>69</sup> This was noted in the context of a scenario where a person with disabilities engaged in a relationship and found herself pregnant.

In terms of personal experiences, when people around her discovered her pregnancy, a Swahili-speaking new mother with a physical disability noted: “Others were happy and others were not happy since I am disabled and yet I am pregnant. How will I care for my baby? My family is not there, but some of the neighbors were happy; others were not. They couldn’t believe I could

become pregnant.”<sup>70</sup>

For an unmarried girl or woman, participants offered that she would possibly hide the pregnancy, keep the child, or her parents, family or sexual partner would force her to have an abortion. Other scenarios mentioned included the family or responsible adolescent boy/man asking the girl or woman to marry. Responses were therefore mixed, across and within groups. While several groups mentioned the pregnant woman or girl would receive antenatal care, the few comments from mothers with disabilities showed that they had very little knowledge regarding what to expect during pregnancy.

When a pregnant girl or woman with disabilities is ready to deliver her baby, participants noted she would do so at the hospital or at home with a traditional birth attendant, her mother, another relative, neighbor or by herself in secret. If she delivers at the hospital, she would go there by foot or by taxi.

Once she arrives at the health facility, participants agreed that she would often experience discrimination and be overlooked. Many participants felt that pregnant women and girls with disabilities would not be treated nicely and with respect by health providers. They cited remarks such as “How can you as a refugee and disabled person be pregnant?”<sup>71</sup> and “Discriminated by the midwives, the nurses would mock her because she is a problem and she is giving birth to another problem.”<sup>72</sup> Indeed, the Swahili-speaking new mother recalled her experience:

*“The staff of the hospital helped although they were not good and there were saying words like, ‘Why is she pregnant if she has a disability?’ The doctors were discriminating me from others because I have a disability. They were delivering others as normal, but because I am a refugee, I waited a long time for the doctor to come and see me.”*<sup>73</sup>

She further noted: “They [persons with disabilities] need to have a lot of courage since they can get a lot of problems, like having relationships and being pregnant. So it is not easy to be a person with a disability, be pregnant and have a child.”<sup>74</sup>

## V.vi. Autonomy around SRH-related decision-making

Participants provided mixed feedback in terms of whether they made decisions about health concerns independently, with their caregivers and/or with health providers. Drug shortages and lack of money to buy prescribed medicines appeared to be a more pressing concern than inclusion in any decision-making. Feedback from refugees with disabilities and caregivers showed that discussions related to common and minor illnesses were largely made by caregivers and health providers, but often with involvement of the individual in question. Several caregivers revealed that this was essential to ensure that the individual with disabilities was willing to take appropriate medicines or undergo treatment. One caregiver also noted that, in fact, her child would take the lead in reminding her when it was time to visit the hospital for follow-up, demonstrating an empowerment process.

Mixed levels of autonomy were seen in decisions that impacted refugees with disabilities' SRH, especially in relation to pregnancy out of wedlock. Somali caregivers in particular noted the real possibility of a forced abortion, citing: "While abortion is not allowed in our religion, we would go ahead and do that to save ourselves from blame,"<sup>75</sup> as well as "It is our reputation that will be tarnished, so we will get rid of the baby."<sup>76</sup> Such measures appeared to also apply to non-disabled persons; hence, the decision to terminate a pregnancy was seemingly based more on marital status and less on disability.

To prevent future pregnancies, participants cited various strategies. Swahili-speakers tended to note that "they decide for themselves because the parents do not advise their girls on the methods to use."<sup>77</sup> The Somalis more often mentioned that families, especially the mothers, would be involved in strategies to prevent further pregnancies. They also shared mixed responses regarding the use of family planning (other than sterilization, which is not permitted in Somali culture) despite their initial rejections: "The first would be a lesson learned. The first pregnancy, she will not kill the baby, but the next

pregnancy, her family would prevent her from getting pregnant. The family would give her contraception like injection or pills."<sup>78</sup> Other mentioned contraceptives included the coil and even emergency contraception. The use of such methods was often divorced from user autonomy; however, several caregivers appeared to agree with the comment: "To protect her, we would do this [give her pills, injections or an IUD], with or without her consent. To save us from blame, we would do this."<sup>79</sup>

Only one person among all consulted in group activities felt "It's no problem if she [unmarried girl with disabilities] becomes pregnant;"<sup>80</sup> no one else shared the assumption that the pregnancy could have been a result of love. Further, only one group—Swahili-speaking women with mild intellectual impairments—defended refugees with disabilities and their ability to have subsequent pregnancies, claiming: "No one can stop because it is her rights. Although she is a person with a disability, she has a right to produce."<sup>81</sup>

The ability of a boy or man with disabilities to impregnate a girl or woman was seen with fewer objections, although responses were also mixed. Swahili-speaking men with disabilities agreed "The boy would be seen as a very strong man"<sup>82</sup> and "Men must be men and they should have as many children as they want."<sup>83</sup> One caregiver additionally noted in relation to her son exploring his sexuality: "I saw my son having lust for women and it scared me so much because I knew it would bring problems to me. [However] whenever he is like that, I am very happy because I know that the child functions normally."<sup>84</sup> On the other hand, Swahili-speaking boys with disabilities noted that "some families disown the boy so he will be left to lead his own life."<sup>85</sup> Additionally, boys discussed that families would "bewitch" him "otherwise they can't force him to go for sterilization."<sup>86</sup> Swahili-speaking boys with mental impairments noted "They take him by force to the doctor for sterilization" and "The boy has to go through counseling to stop him from impregnating girls again."<sup>87</sup>

Despite severely curtailed freedoms to make SRH-related decisions, several female participants—especially those who were unable to leave their

homes—expressed desires to have children and families. However, the Swahili-speaking new mother shared that the man who impregnated her left after discovering her pregnancy,<sup>88</sup> and some home-based women were observed to be raising children without a stable partner. Such women were often blamed by family members for increasing caregiver responsibilities in the home.<sup>89</sup>

### V.vii. Perceptions around treatment of persons with disabilities

All participants agreed that violence against refugees with disabilities is unacceptable. Nevertheless, not all participants and groups agreed on what constituted violence against a persons with disabilities, and what, if any, types of treatment would be acceptable under certain circumstances.

Of the 28 scenarios presented to group activity participants, only three of the six seemingly positive situations were perceived by all groups as acceptable treatment. These were: “Persons with disabilities and persons without disabilities are friends;” “Non-violent, happy family where persons with disabilities are included;” and “Someone offering help to a person with disabilities.” On the other hand, groups showed varying levels of agreement over scenarios such as “controlling money,” “promoting traditional or cultural myths” and “persons with disabilities as a leader in the community.” See Table 2 for details on how participants sorted scenarios across groups.

Within groups, four issues were most contentious: “forced sterilization,” “controlling money,” “promoting traditional or cultural myths about persons with disabilities” and “a person with disabilities as a leader of a community.” Table 3 notes how participants categorized scenarios within groups. Four of 16 groups noted that forced sterilization could be acceptable depending on the circumstances, with comments, including “If a person is mentally ill, then sterilization can be done to prevent unwanted pregnancies, but if not, then she can take a guided decision”<sup>90</sup> and “Forcing a person with disabilities to be sterilized is both [acceptable and unacceptable]. It will depend on the kind of disability.

When a person has a mental [intellectual] problem, the caretaker is the one to decide. If the person has a physical impairment, the person could produce. If the person has a heavy disability and is disturbing the family, they may have the person sterilized.”<sup>91</sup> Eleven of 16 groups, however, collectively agreed that forced sterilization was unacceptable, citing reasons that it was violence or against a person’s will. All adolescent groups categorized forced sterilization as unacceptable; counter responses came from adults.

Only five of 16 groups unanimously felt that controlling money was unacceptable, while two concluded that it was acceptable. The rest provided mixed responses, largely based on the type of disability, or if they interpreted “controlling” as “helping.” Participants often justified that it was acceptable to control money of persons with intellectual or visual impairments, although such claims were not echoed by persons with these impairments. A group of adult Somali women with mild intellectual impairments responded that “controlling money is unacceptable because persons with disabilities have a right to have their money to give to whom they want.”<sup>92</sup> Two groups of Somali adolescent girls further pointed out: “The person that is controlling can take advantage of the person with a disability. When you are blind or deaf, they say they have paid but may be deceiving.”<sup>93</sup>

Regarding the promotion of traditional or cultural myths about persons with disabilities, groups that recognized the possibility of positive messaging around persons with disabilities shared that such myths could be acceptable. As for persons with disabilities serving as a leader in her or his community, while 12 groups were in favor, four groups provided mixed or negative responses. Mixed feedback included “A person with disabilities as a leader of the community is both [acceptable and unacceptable] because it will depend on the type of disability. If they have a heavy disability, they should not be a leader”<sup>94</sup> and “She can’t be a leader because she is disabled and no one will respect her.”<sup>95</sup> Such attitudes reflect refugees with disabilities’ negative images about themselves and their peers. For the most part, however, comments were strong around

Table 2: Variability of treatment categories *across* groups

Acceptable	Unacceptable	Mixed Responses
<ul style="list-style-type: none"> <li>• Persons with disabilities and persons without disabilities are friends</li> <li>• Non-violent, happy family where persons with disabilities are included</li> <li>• Someone offering help to a person with disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Rape of an adult</li> <li>• Rape of a child</li> <li>• Forced prostitution</li> <li>• Molestation</li> <li>• Beating of an adult with a disability</li> <li>• Neglect</li> <li>• Violence with words</li> <li>• Making the person with disabilities see traumatic acts</li> <li>• Rejecting or abandoning the person with disabilities</li> <li>• Not allowing opportunity</li> <li>• Human trafficking</li> <li>• Low or no payment for work</li> </ul>	<ul style="list-style-type: none"> <li>• Sexual exploitation and abuse</li> <li>• Early marriage</li> <li>• Beating of a child with a disability</li> <li>• Forced sterilization</li> <li>• Denying access to services</li> <li>• Child labor</li> <li>• Controlling money</li> <li>• FGM (Somali)</li> <li>• Child sacrifice</li> <li>• Promoting traditional or cultural myths</li> <li>• Persons with disabilities in safe, happy, romantic relationships</li> <li>• A child with disabilities attending mainstream school</li> <li>• A person with disabilities as a leader in the community</li> </ul>

“she has a right to be a leader if she is educated and she should not be discriminated because of her disability”<sup>96</sup> and “a person with disabilities as a leader of a community is acceptable because persons with disabilities have a right to participate in leadership at community and national levels, and they have good leadership skills.”<sup>97</sup> The men’s groups unanimously agreed that refugees with disabilities could serve as leaders.

Other mixed responses were a reflection of cultural and social beliefs held by participants, or of how

the scenario was interpreted. For example, “early marriage” was most contentious among the Somalis, some of whom agreed that it was acceptable, citing the Prophet Mohammad’s marriage, while others disagreed, saying: “The man is older than her and may not be able to fulfill her sexual pleasure. Forcing her is not good.”<sup>98</sup> Similar disagreement was observed over female genital mutilation (FGM), although more participants regarded it as unacceptable rather than acceptable. Those who felt it acceptable cited tradition, while those who disagreed noted, “If a girl is cut, her menstrual periods are very painful and giving birth



Table 3: Variability of treatment categories *within* groups

Acceptable	Unacceptable	Mixed Responses
<ul style="list-style-type: none"> <li>• Forced sterilization</li> <li>• Controlling money</li> <li>• Non-violent, happy family where persons with disabilities are included</li> <li>• Persons with disabilities and persons without disabilities are friends</li> <li>• Persons with disabilities in safe, happy, romantic relationships</li> <li>• Someone offering help to a person with disabilities</li> <li>• A child with disabilities attending mainstream school</li> <li>• <b>A person with disabilities as a leader in the community</b></li> </ul>	<ul style="list-style-type: none"> <li>• Rape of an adult</li> <li>• Rape of a child</li> <li>• Sexual exploitation and abuse</li> <li>• Forced prostitution</li> <li>• Molestation</li> <li>• Early marriage</li> <li>• Beating of an adult with a disability</li> <li>• Beating of a child with a disability</li> <li>• Neglect</li> <li>• <b>Forced sterilization</b></li> <li>• Denying access to services</li> <li>• Child labor</li> <li>• Violence with words</li> <li>• Making the PWD see traumatic acts</li> <li>• Rejecting or abandoning the PWD</li> <li>• Controlling money</li> <li>• Not allowing opportunity</li> <li>• Human trafficking</li> <li>• Low or no payment for work</li> <li>• FGM (Somali)</li> <li>• Child sacrifice</li> <li>• <b>Promoting traditional or cultural myths</b></li> <li>• Persons with disabilities in safe, happy, romantic relationships</li> <li>• A child with disabilities attending mainstream school</li> <li>• A person with disabilities as a leader in the community</li> </ul>	<ul style="list-style-type: none"> <li>• Sexual exploitation and abuse</li> <li>• Early marriage</li> <li>• Beating of a child with a disability</li> <li>• Forced sterilization</li> <li>• Denying access to services</li> <li>• Child labor</li> <li>• <b>Controlling money</b></li> <li>• FGM (Somali)</li> <li>• Child sacrifice</li> <li>• Promoting traditional or cultural myths</li> <li>• A person with disabilities as a leader in the community</li> </ul>

*Bold font indicates that the majority of groups categorized the card as “acceptable,” “unacceptable” or both.*

to babies will be very difficult.”<sup>99</sup> “Sexual exploitation and abuse (SEA)” and “child labor” were additionally seen as unacceptable by all groups except one, where responses were mixed. Comments in the dissent included “SEA is both. It is acceptable if it is your choice. It will depend on you. Sometimes you may accept to sleep with him if you have a problem”<sup>100</sup> and “Child labor is acceptable because they are teaching the child to do work.”<sup>101</sup> Both reflect social circumstances or possible tradition.

On the other hand, surprising comments of typically acceptable behavior scenarios included comments such as: “Persons with disabilities in a safe, happy romantic relationship is unacceptable because if you have a physical disability and you have to get married and you get pregnant, you are increasing your problems.”<sup>102</sup> However, all participants except for one group of Swahili-speaking women with mental impairments agreed that persons with disabilities have “a right to love.”<sup>103</sup>

While the degree of acceptable touching was probed to some degree, the study team did not hear of any concerning remarks, even among those who required support in daily routines, such as dressing, going to the toilet and cleaning. However, the lack of disclosure may have been a result of a group environment or presence of caregivers in some individual interviews.

### V.viii. Safety concerns

Responses to questions around safety yielded interesting findings. While the study assumed participants would associate safety with physical or sexual safety, participants primarily associated safety with physical accessibility. This was the primary reason that among the 24 photographs of community landmarks and persons, only one was unanimously voted by all 16 groups and two prompted individuals to be unsafe (water collection), and the level of agreement varied across and within groups. See Table 4 for details of categorization across groups, where participants sorted cards into three piles of safe, unsafe or both. Caregivers, on the other hand, more often associated

safety with risks of physical or sexual violence.

Regarding water collection points, several groups mentioned that it was unsafe, especially for persons who are blind, persons with intellectual impairments and persons with physical impairments. Reasons were related to risks of falling and drowning, the inability to cross to the other side, lack of cleanliness or presence of waterborne diseases. For example, one Somali adolescent who is home-based noted: “Water collection is not safe because you can’t walk there well and you can’t swim like any other persons, especially the blind.”<sup>104</sup> Girls from the group of Swahili-speaking persons with intellectual impairments further shared, “For those who have a mental [intellectual] challenge, they are not advised to come near that water point.”<sup>105</sup>

Participants with disabilities generally agreed that they felt most unsafe by the toilets and in their neighborhoods. Both of these landmarks were cited as locations where risk of attack and rape were possible. Indeed, 15 of 16 groups, and 11 of 16 groups unanimously agreed that the toilets and the neighborhood were unsafe, respectively. The only group that did not feel the toilets were unsafe were Swahili-speaking adolescent boys with intellectual impairments. Common comments from all ages and languages included “Toilets are not safe because it is located outside, and when you need to go to the toilet at night, thieves can take advantage and rape you”<sup>106</sup> and “Sometimes when we go to the toilet at night, people get raped since the toilets are open. People can get candida from the toilets since it is used by a large number of people.”<sup>107</sup>

Regarding the neighborhood, common comments included “The neighborhood is unsafe because there are many corners where a disabled person can be raped”<sup>108</sup> and “The neighborhood is not safe because there are some hills which are difficult to climb and some holes which the blind person can fall into. It also has a dark corner where someone can rape you from there, hence getting HIV infections.”<sup>109</sup> The neighborhood was also cited as unsafe by participants who were home-based, one of whom noted, “The neighborhood is unsafe since I might get raped when it gets

Table 4: Variability in safety categories <i>across</i> activities		
Safe	Unsafe	Mixed Responses
	<ul style="list-style-type: none"> <li>• Water collection</li> </ul>	<ul style="list-style-type: none"> <li>• Aid workers</li> <li>• Counselor</li> <li>• Food distribution</li> <li>• Main road</li> <li>• Market</li> <li>• Mobile court</li> <li>• Mulago Referral Hospital</li> <li>• Neighborhood</li> <li>• KCCA</li> <li>• Police station</li> <li>• Public taxi and boda boda</li> <li>• Disability group</li> <li>• Leader with disabilities</li> <li>• Red Cross office</li> <li>• Refugee church</li> <li>• Refugee houses</li> <li>• Religious leader</li> <li>• Registration</li> <li>• RLP office</li> <li>• School for the blind</li> <li>• Shops and workplace</li> <li>• Toilet</li> <li>• Waiting area at OPM</li> </ul>

dark.”<sup>110</sup> No participant mentioned recent incidents of sexual violence, although several adult women—including those with mental and hearing impairments—disclosed past and even multiple incidents that had occurred prior to displacement. A Deaf participant for example, shared that her pregnancies were all a result of rape in her youth before fleeing to Uganda.<sup>111</sup>

While most photos yielded no major differences between sexes and age, all boys’ and men’s groups categorized the police station as unsafe, while

women’s and girls’ groups presented more mixed responses. Similarly, all groups of adolescents categorized the market as unsafe, while more variation was seen among groups of adult women.

The neighborhood and neighbors were particularly concerning for caregivers who noted risks of sexual violence and trouble with neighbors: “With the neighbors, because when I sometimes go away, I feel like they will rape my daughter or that they will accuse her of doing something that she has not done. For example,

that she has spoilt someone's things."<sup>112</sup> Another agreed: "Whenever the child is not at home; I remain with fear because I feel that anything can happen to the child. The child is at risk. If it's a girl, she can be raped or can engage in sexual relationships."<sup>113</sup> A third echoed, "When my daughter is not at home, I fear that she can be raped and get diseases."<sup>114</sup> A fourth mentioned: "Security is a problem. When the parents go to search for food for the siblings, neighbors beat them [the person with a disability]. When they spoil the neighbors' property, they create hatred just because of the child."<sup>115</sup> A caregiver of a home-based adolescent agreed: "Risk of death and conflicts between other families can rape a child or beat a child harmfully."<sup>116</sup>

Caregivers had grave concerns regarding their family members, especially adolescent girls with disabilities. In discussions of the differences between having girls and boys with disabilities in their family, feedback included:

- "A boy can be left with family friends and neighbors, but the girl is very delicate. She can easily be raped, hence HIV/AIDS, sexually transmitted diseases and unwanted pregnancy. The burden of the pregnancy will be left to the parents."<sup>117</sup>
- "We experience new problems, such as they [girls] don't cover their body. They don't feel shame. As a normal girl, you feel embarrassment, but a child with an intellectual impairment cannot since she doesn't know how to control herself. When the girl has an intellectual problem, when she goes out, other men can take advantage of her, like raping her."<sup>118</sup>
- "Taking care of the girl is different from boys because when girls start to experience their periods they simply cannot take care of their hygiene, and most times, I forget to count her days in order to prepare for the menstruation. She can easily be raped or forced to have sex which ends up with diseases such as HIV/AIDS, unwanted pregnancies and sexually transmitted diseases which are not common among boys."<sup>119</sup>
- "Boys can also be influenced by their peers to take marijuana. Some women can take advantage of them

by forcing them to have sex without their consent. This leads to catching diseases, such as HIV/AIDS, sexually transmitted diseases and many others."<sup>120</sup>

- "Some house boys take advantage of the mentally ill girls, especially when their parents have gone to work. Some girls are impregnated; others are infected with diseases such as sexually transmitted diseases. Others marry them, disappear with them or sacrifice them. This is not common with boys."<sup>121</sup>
- "Some doctors take advantage and have sex with the disabled girl child because they do not speak, hear or even understand that these acts continue to disrupt the girls."<sup>122</sup>

Despite grave security concerns and likely due to the parameters set for the study to ensure ethical and safety measures, neither caregivers nor refugees with disabilities disclosed specific cases of sexual violence against children or adolescents with disabilities in their present displacement environment. Further, several participants with disabilities were aware of post-rape care and the benefits of seeking health care after experiencing sexual violence. They raised access to medicines to prevent pregnancy and HIV, as well as protection and legal services, as benefits to seeking care. They appeared to have received this information from health campaigns and messaging.

Other places where refugees with disabilities felt unsafe were generally related to physical accessibility—if a landmark had stairs or was close to a road or water, participants felt it unsafe, especially for the physically or visually impaired. The presence of stairs, inaccessible furniture (benches, etc.) and unstable infrastructure (metal sheet walls or mud homes) also prompted many participants to declare that locations such as health care facilities, the Office of the Prime Minister (OPM), the RLP office, a refugee church and their homes were "unsafe." Other unsafe locations that participants named beyond the photographed landmarks were the bush, forest, bridge, refugee camp, bar, prison and police detention. Both group and home-based participants also mentioned the home when they were home alone.



In the few groups and individuals that felt the leader with disabilities or religious leader were unsafe persons, responses largely showed participants associating safety with the environment where the person was photographed, rather than the category of the person in general. No one mentioned physical security risks associated with leaders in their community. See Table 5 for details on how participants sorted landmarks within groups.

### V.ix. Coping strategies, protective and facilitating factors

Through activities, participants revealed that some safe spaces existed, especially for mental and emotional respite. A counselor from RLP was seen as safe by 13 groups and four individuals. The participants with mental and intellectual impairments appeared to especially appreciate the role that RLP counselors played in alleviating their concerns. Among those who agreed the counselor was safe, comments included:

Safe	Unsafe	Mixed Responses
<ul style="list-style-type: none"> <li>• <b>Aid workers</b></li> <li>• <b>Counselor</b></li> <li>• <b>Food distribution</b></li> <li>• Market</li> <li>• <b>Mobile court</b></li> <li>• Mulago Referral Hospital</li> <li>• Neighborhood</li> <li>• <b>KCCA</b></li> <li>• Police station</li> <li>• Public taxi and boda boda</li> <li>• <b>Disability group</b></li> <li>• <b>Leader with disabilities</b></li> <li>• <b>Red Cross office</b></li> <li>• Refugee church</li> <li>• Refugee houses</li> <li>• <b>Religious leader</b></li> <li>• <b>Registration</b></li> <li>• RLP office</li> <li>• <b>School for the blind</b></li> <li>• Toilet</li> <li>• <b>Waiting area at OPM</b></li> </ul>	<ul style="list-style-type: none"> <li>• Aid workers</li> <li>• Counselor</li> <li>• Food distribution</li> <li>• <b>Main road</b></li> <li>• <b>Market</b></li> <li>• Mobile court</li> <li>• <b>Mulago Referral Hospital</b></li> <li>• <b>Neighborhood</b></li> <li>• KCCA</li> <li>• <b>Police station</b></li> <li>• <b>Public taxi and boda boda</b></li> <li>• Leader with disabilities</li> <li>• Red Cross office</li> <li>• <b>Refugee church</b></li> <li>• <b>Refugee houses</b></li> <li>• Religious leader</li> <li>• Registration</li> <li>• <b>RLP office</b></li> <li>• School for the blind</li> <li>• <b>Shops and workplace</b></li> <li>• <b>Toilet</b></li> <li>• Waiting area at OPM</li> <li>• <b>Water collection</b></li> </ul>	<ul style="list-style-type: none"> <li>• Counselor</li> <li>• Food distribution</li> <li>• Main road</li> <li>• Market</li> <li>• Mobile court</li> <li>• Mulago Referral Hospital</li> <li>• Neighborhood</li> <li>• KCCA</li> <li>• Police station</li> <li>• Public taxi and boda boda</li> <li>• Disability group</li> <li>• Leader with disabilities</li> <li>• Red Cross office</li> <li>• Refugee church</li> <li>• Refugee houses</li> <li>• Religious leader</li> <li>• Registration</li> <li>• RLP office</li> <li>• School for the blind</li> <li>• Shops and workplace</li> <li>• Toilet</li> <li>• Waiting area at OPM</li> </ul>
<p><b><i>Bold font indicates that the majority of groups and interview participants selected the photograph as “safe” or “unsafe.”</i></b></p>		

“The counselor is safe because you can receive Mama Eunice [counselor] there. The place is safe and clean;”<sup>123</sup> “Persons with disabilities have a lot of problems and they need counselors more than others;”<sup>124</sup> and “When I met my counselor and she comforts me, I immediately forget my problems.”<sup>125</sup> Many participants, particularly the home-based, also said they felt most safe when they were with their family members, caregivers or a support group for persons with disabilities.

Several caregivers felt schools were a protective space for their children with disabilities. They mentioned interactions with other children and the acquisition of communication skills as very helpful. For example, one parent noted: “Before she went to school, she would escape from the house and move to neighboring houses. After being enrolled in school, people stopped taking advantage of her such as fetching water from the well and sending her to the shop.”<sup>126</sup> Another said: “The child before going to school had a lot of anger, but now after going to school, he has learnt to interact with other children. Before, he would fight, but now he reports to the mother in case someone has insulted him.”<sup>127</sup> A third agreed: “When she was young, she would hardly understand, but when she was enrolled into school, there is an improvement. Now she can help the parents especially with English interpretation.”<sup>128</sup>

When participants were asked what they could do to serve as agents for change, a few mentioned that they could direct others to services where available, and explain to them how they operate. For the most part, however, participants shared few strategies to help themselves.

## V.x. Recommendations from refugees with disabilities and caregivers

Participants and caregivers suggested various ways that existing barriers and challenges can be addressed in relation to access to SRH services. In addition to resettlement, these included:

- Train service providers on how to kindly and respectfully work and communicate with refugees with disabilities.
- Provide fast-track options to good quality health and counseling services, where medicines are not out of stock.
- Employ sign language and other language interpreters in health facilities to improve communications, especially to prevent miscommunication that could lead to misdiagnosis and prescriptions of the wrong medicine.
- Provide referrals to other facilities if a patient's case cannot be handled in one facility, instead of asking the patient to come back many times.
- Ensure timely and appropriate follow-up of refugees with disabilities in hospitals so that staff are informed of the results and well-being of the individual.
- Provide information about existing services through workshops, relatives and fellow refugees.
- Provide assistive devices more readily.
- Provide language classes, educational opportunities and vocational training for refugees with disabilities and caregivers, so that they can communicate better with service providers and have the opportunity to work and earn an income.

## VI. Key Considerations

This study among Swahili-, Somali- and Kinyarwanda-speaking and Luganda-signing refugee women, men and adolescents with disabilities showed a wide range and mix of findings. Examining the rich findings in the context of the study and setting of Kampala, several observations can be made.

1. Many people with mental disabilities in the Kampala context appeared to have acquired their impairment as a result of conflict-related trauma incurred in their home countries, which often reflected other SRH concerns. The study had a high proportion of participants who identified themselves as having mental impairments; partially as a result of the clientele that RLP serves. While unprompted, participants frequently associated the causes of their impairment with violence (as witness or as victim) that they had experienced prior to displacement. Further, several women with mental disabilities described having experienced past rape, and reflected related concerns such as early and forced marriage. Past traumatic experiences continued to have implications for survivors.
2. Findings often reflected social prejudices, even among refugees with disabilities towards other persons with disabilities. This was particularly seen among participants with mental and intellectual impairments who possessed very low self-esteem and self-value. Further, groups of persons with physical impairments were more likely to show unequal attitudes towards those with intellectual impairments. This reflected wider societal attitudes towards persons with intellectual impairments, especially in relation to autonomy over exercising SRH rights, including their choice to use or not to use family planning methods or terminate a pregnancy. Scenarios around an unmarried pregnant woman with disabilities also showed little belief that persons with disabilities could have become pregnant as a result of love, despite most groups agreeing that they have a right to equal, romantic relationships.
3. Risks of sexual violence were voiced by persons with disabilities and caregivers in particular. Girls with intellectual disabilities were perceived as most vulnerable due to a lack of awareness of socially acceptable behaviors that may make them a target for perpetrators of such violence. While all disclosed incidents occurred prior to displacement, such cases mark specific concerns for persons with disabilities. Caregivers were further concerned about safety issues for adolescents with disabilities, especially when they themselves were away from home.
4. Women with disabilities, particularly those who are isolated in their homes, may be in less stable relationships and lack support in parenting. Among those whom the study team interviewed, one new mother shared that the man that impregnated her left after discovering her pregnancy. Data collectors also learned of other instances where refugees with disabilities became pregnant and bore children without the presence of the father. In all of these instances, women reported that they wanted to produce and bear children. Such women were often blamed by family members for increasing caregiver responsibilities, suggesting that they may require additional support to raise their child and raising concerns about abuse and exploitation in and outside of the family.
5. Despite successful outreach by existing programs, as demonstrated by higher awareness levels among some refugees with disabilities, more SRH outreach and services are necessary to clarify the high degree of misconceptions, as well as meet interest levels of persons with disabilities in receiving more information and services. The body mapping exercise revealed misconceptions around family planning methods and STIs in particular, as well as the need to provide SRH information and guidance on relationships to adolescents, and even to parents with disabilities who missed opportunities to receive such information themselves to convey to their children. Reaching out to refugees with disabilities who are unable to leave

their homes can also increase opportunities for them and their caregivers to receive information from external sources.

6. Recommendations offered by refugees with disabilities to improve their SRH experience often reflected improvements in quality of care, as well as activities to empower themselves. Improving provider attitudes and employing interpreters—sign and other languages—were often mentioned as practical ways to reduce stigma and address prevailing negative sentiments. Participants also provided ways that they, themselves, could overcome challenges, including the expressed desire to learn English and earn an income, so that they are not dependent on aid and external factors, and can be in more control of their situations



Data collectors re-creating the safety map as developed by group participants.

## VII. Conclusion

This study among refugees with a variety of impairments is one of three studies that explored the intersections between SRH and disability in humanitarian settings. Findings and recommendations offered by refugees with disabilities in this study will be used to advocate for disability inclusion in existing SRH services for refugees with disabilities in Kampala, refugee inclusion among the national DPO movement, as well as in other humanitarian settings more broadly.

In the Global Appeal 2014-2015, UNHCR notes that its 2014 comprehensive target goals for SRH and HIV services are to provide optimal access to preventive and clinical care. Its specific targets for 1) percentage of rape survivors receiving post-exposure prophylaxis for HIV within 72 hours of the incident, and 2) the extent to which persons of concern have access to HIV services are at 100% for Congolese, Somali, Rwandan, Burundian, South Sudanese and Sudanese refugees and asylum seekers. For urban refugees, its target for the latter indicator is at 90%.<sup>129</sup> For such high goals to be attained, it would be important to obtain a more accurate figure of the real number of refugees with disabilities in Kampala. Targeted outreach and emphasis must also be placed on meeting the SRH needs of refugees with disabilities to realize the rights of this vulnerable, but resilient group.

*Reports on this study produced for participants in Kinyarwanda, English, Somali and Swahili are available at [wrc.ms/srh-disability-2014-uganda](http://wrc.ms/srh-disability-2014-uganda).*



## Notes

1. In this report, “persons with mental disabilities” refers to persons with mental health conditions and/or those who are users and/or survivors of psychiatry. The term “persons with psychosocial disabilities” is sometimes also used to describe this group of persons with disabilities. World Network of Users and Survivors of Psychiatry. 2008. *Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities*, p. 9. <http://www.disabilityrights-fund.org/resource/implementation-manual-united-nations-convention-rights-persons-disabilities.html>.
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7. 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://usidc.org/index.cfm/news\\_forgetting-sisters-a-report-on-violence-against-women-with-disabilities-an-overview-of-its-nature-scope-causes-and-consequences](http://usidc.org/index.cfm/news_forgetting-sisters-a-report-on-violence-against-women-with-disabilities-an-overview-of-its-nature-scope-causes-and-consequences).
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56. Caregiver, Somali focus group discussion; December 19, 2013.
57. Caregiver, Somali focus group discussion; December 19, 2013.
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60. Adult male participant, Swahili intellectual impairment group; January 9, 2014.
61. Adult female participant, Swahili physical, vision and mental impairment group; December 17, 2013.
62. Adult male participant, Swahili intellectual impairment group; January 9, 2014.
63. Caregiver of a 16 year old Swahili-speaking girl with an intellectual impairment; January 7, 2014.
64. Adult male participant, Swahili intellectual impairment group; January 9, 2014.
65. Adult male participant Swahili physical, vision and mental impairment group; December 17, 2013.
66. Adolescent girl participant, Kinyarwanda physical, vision and mental impairment group; December 19, 2013.
67. Adolescent girl participant, Somali physical, vision and mental impairment group; December 20, 2013.
68. Adult female participant, Somali intellectual impairment group; January 7, 2014.
69. Adult female participant, Luganda sign group; January 6, 2014.
70. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
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72. Adult male participant Swahili physical, vision and mental impairment group; December 17, 2013.
73. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
74. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
75. Caregiver, Somali focus group discussion; December 19, 2013.
76. Caregiver, Somali focus group discussion; December 19, 2013.
77. Adolescent girl participant, Swahili physical, vision and mental impairment group; December 18, 2013.
78. Adult female participant Somali physical, vision and mental impairment group; December 17, 2013.
79. Caregiver, Somali focus group discussion; December 19, 2013.
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81. Adult female participant, Swahili intellectual impairment group; January 9, 2014.
82. Adult male participant, Swahili physical, vision and mental impairment group; December 17, 2013.
83. Adult male participant, Swahili physical, vision and mental impairment group; December 17, 2013.
84. Caregiver, Swahili focus group discussion; December 19, 2013.
85. Adolescent boy participant, Swahili intellectual impairment group; January 8, 2014.
86. Adolescent boy participant, Swahili physical, vision and mental impairment group; December 18, 2013.
87. Adult male participant, Swahili mental impairment group; December 20, 2013.
88. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
89. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
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92. Adult female participants, Somali intellectual impairment group; January 7, 2014.
93. Adolescent girl participant, Swahili physical, vision and mental impairment group; December 18, 2013.
94. Adult female participant, Kinyarwanda physical, vision and mental impairment group; December 18, 2013.
95. Adult female participant, Somali intellectual impairment group; January 7, 2014.
96. Adolescent girl participant, Somali physical, vision and mental impairment group; December 20, 2013.
97. Adult male participants, Swahili physical, vision and mental impairment group; December 17, 2013.
98. Adult female participant Somali physical, vision and mental impairment group; December 17, 2013.
99. Adolescent girl participant, Somali physical, vision and mental impairment group; December 20, 2013.
100. Adult female participant, Kinyarwanda physical, vision and mental impairment group; December 18, 2013.
101. Adolescent girl participant, Swahili intellectual impairment group; January 8, 2014.
102. Adult female participant, Swahili mental impairment group; December 20, 2013.
103. Adolescent girl participant, Kinyarwanda physical, vision and mental impairment group; December 19, 2013.
104. Interview with a 16 year old home-based Somali; December 20, 2013.

105. Adolescent girl participant, Swahili intellectual impairment group; January 8, 2014.
106. Interview with a 16 year old Swahili-speaker with multiple impairments; January 6, 2014.
107. Adult female participant, Kinyarwanda physical, vision and mental impairment group; December 18, 2013
108. Adult female participant, Swahili physical, vision and mental impairment group; December 17, 2013.
109. Adolescent girl participant, Swahili intellectual impairment group; January 8, 2014.
110. Interview with 28 year old Somali-speaking new mother with a disability; December 19, 2013.
111. Adult female participant, Luganda sign group; January 6, 2014.
112. Mother of interview with a 16 year old Swahili-speaker with multiple impairments; January 6, 2014
113. Caregiver, Swahili focus group discussion; December 19, 2013.
114. Caregiver, Swahili focus group discussion; December 19, 2013.
115. Caregiver, Swahili focus group discussion; December 19, 2013.
116. Caregiver of a 16 year old Swahili-speaking girl with an intellectual impairment; January 7, 2014.
117. Caregiver of a 16 year old Swahili-speaking girl with an intellectual impairment; January 7, 2014.
118. Caregiver, Somali focus group discussion; December 19, 2013.
119. Caregiver, Swahili focus group discussion; December 19, 2013.
120. Caregiver, Swahili focus group discussion; December 19, 2013.
121. Caregiver, Swahili focus group discussion; December 19, 2013.
122. Caregiver, Swahili focus group discussion; December 19, 2013.
123. Adult female participant, Swahili mental impairment group; December 20, 2013.
124. Adolescent girl participant, Swahili intellectual impairment group; January 8, 2014.
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## VIII. ANNEXES

Annex 1: List of cards depicting treatment of refugees with disabilities

Annex 2: List of photos from safety mapping exercise

Annex 3: Images of cards depicting treatment of refugees with disabilities (online at [http://wrc.ms/SRH\\_disab\\_cards](http://wrc.ms/SRH_disab_cards))

Annex 4: Photos from safety mapping exercise (online at [http://wrc.ms/SRH\\_disab\\_photos\\_Uganda](http://wrc.ms/SRH_disab_photos_Uganda))



## Annex 1: List of cards depicting treatment of refugees with disabilities

List of cards
<b>Sexual violence</b>
Rape of an adult
Rape of a child
Sexual harassment
Sexual exploitation and abuse
Forced prostitution
Early marriage
<b>Physical violence</b>
Beating of an adult with a disability by a family member
Beating of a child with disabilities
Neglect
Forcing a person with disabilities to be sterilized
Denying access to services
Child labor
<b>Emotional violence</b>
Violence with words
Making the person with a disability see traumatic acts
Rejecting or abandoning persons with disabilities
<b>Economic violence</b>
Controlling money
Not allowing opportunity
Human trafficking
Non-payment or low pay for work
<b>Harmful traditional practices</b>
Female genital cutting
Child sacrifice
Promoting traditional or cultural myths about a person with disabilities
<b>Non-violence</b>
Non-violent, happy family where persons with disabilities are included
Persons with disabilities and persons without disabilities adolescents are friends
Persons with disabilities in safe, happy romantic relationships
Someone offering help to a person with disabilities
A child with disabilities attending mainstream school
A person with disabilities as a leader of a community

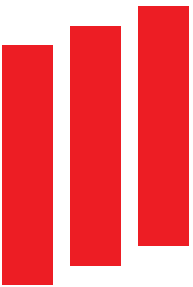
See cards at [http://wrc.ms/SRH\\_disab\\_cards](http://wrc.ms/SRH_disab_cards).

## Annex 2: List of photos from safety mapping exercise

List of Photos
Aid workers
Counselor
Food distribution
Main road
Market
Mobile court
Mulago Referral Hospital
Neighborhood
New maternity wing at Kisenyi Health Center IV
Police station
Public taxi and boda boda
Disability group
Leader with disabilities
Red Cross office
Refugee church
Refugee houses
Religious leader
Registration
RLP office
School for the blind
Shops and workplace
Toilet
Waiting area at OPM (Office of the Prime Minister)
Water collection

See safety mapping photos at [http://wrc.ms/SRH\\_disab\\_photos\\_Uganda](http://wrc.ms/SRH_disab_photos_Uganda).





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