



## **“The woman can decide for herself”**

The Intersection of Sexual and Reproductive Health and Disability for Refugees in Kakuma Refugee Camp, Kenya



## 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.

The International Rescue Committee (IRC) provides services to people affected by humanitarian emergencies around the world. In Kakuma Refugee Camp the IRC provides health, nutrition, HIV and protection services, and supports human rights, refugee rights and equal access to services. IRC also provides support to persons with disabilities—inclusive of those with mental impairments—through providing community-based rehabilitation, assistive devices and occupational therapy for children.

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## Acronyms & Abbreviations

|       |   |
|-------|---|
| CRPD  | Convention on the Rights of Persons with Disabilities       |
| DPO   | Organization of Persons with Disabilities                   |
| GBV   | Gender-based violence                                       |
| IASC  | Inter-agency Standing Committee                             |
| IAWG  | Inter-agency Working Group on Reproductive Health in Crises |
| ICPD  | International Conference on Population and Development      |
| IEC   | Information, education and communication                    |
| IRC   | International Rescue Committee                              |
| JRS   | Jesuit Refugee Service                                      |
| LWF   | Lutheran World Federation                                   |
| NCPWD | National Council for Persons with Disabilities              |
| NGO   | Nongovernmental organization                                |
| PWD   | Person with a disability                                    |
| SRH   | Sexual and reproductive health                              |
| STI   | Sexually transmitted infection                              |
| TBA   | Traditional birth attendant                                 |
| 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 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) and the International Rescue Committee (IRC) undertook a qualitative examination of the specific risks, needs and barriers for Somali and other refugees with disabilities to accessing SRH services in Kakuma refugee camp, Kenya, 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 time lines 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 Kakuma refugee camp is one of three studies exploring the intersections between SRH and disability in humanitarian settings. In the Kakuma study, a total of 96 refugees with disabilities participated in the study, of whom 62 were women and girls, and 34 were men and boys. Seventeen caregivers and family members of refugees with disabilities were also consulted. Participants were consulted in Somali, Kiswahili, Arabic, English and Somali sign.

### Key Findings

- **Overarching concerns:** Refugees with disabilities noted long wait times for services, lack of disability accommodations during food and non-food item distributions, and limited disability services as general challenges in the camp. The need for assistive devices was also raised.
- **Awareness of SRH concepts and services:** Both adolescent and adult participants frequently listed IRC and FilmAid as agencies that provide SRH information to refugees with disabilities. Adolescents with disabilities who attended school seemed to know more than adults about reproductive organs, including their functions. Most participants were aware of HIV, although awareness of sexually transmitted infections (STIs) varied across groups. Boys and men appeared to know less about STIs than girls and women who could cite one or two symptoms. Awareness of STIs, as well as contraceptives, was low among participants with intellectual disabilities. Among those who were unable to leave their homes, half had been informed of HIV as well as STIs, and those who were familiar with HIV/STIs had heard of at least one contraceptive method. To prevent pregnancy, group participants most often cited short-term methods (condoms, pills and injectables), followed

by long-acting methods (intrauterine devices and implants). Adolescents only noted short-term methods; no participant raised male or female sterilization as a method to prevent pregnancy.

- **Experiences around use of health and SRH services:** A sizeable number of refugees with disabilities and caregivers said that they were satisfied with existing health services in the camp. A larger number of refugees with disabilities and their caregivers, however, shared concerns regarding long wait times; diversity of languages spoken in the camp and lack of sign language interpreters; transport for refugees with physical impairments; and discrimination and preferential treatment of those related to service providers. For Somali women with disabilities, the sex of the health provider appeared to impact their confidence and ability to speak about SRH, including pregnancy-related concerns. No participant mentioned that there was a lack of service points to receive SRH information and services; accessibility of existing resources appeared the greater challenge.
- **Experiences around romantic relationships:** Participants treated questions around adolescents with disabilities having romantic relationships as natural in a person's life course. Feedback varied regarding the acceptability of relationships; Somali adolescents felt some parents would reject the relationship and prefer that the child focus on completing her education. Abstinence was the most popular suggestion for adolescents to prevent unplanned pregnancy. Those with physical, mental<sup>1</sup> and hearing disabilities listed parents, friends, relatives, teachers, neighbors, religious leaders, churches/mosques, doctors, the IRC clinic, FilmAid and community health workers/promoters as sources of health information and relationship advice. Those with mild intellectual disabilities offered more mixed responses; some felt that no one would advise, while others felt friends and relatives would advise.
- **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. If the pregnant woman or girl with disabilities is unmarried, participants felt she may be seen as a prostitute and stigmatized by her family and community. No participant viewed the pregnancy as a result of a romantic or equitable relationship. Pregnant adolescent girls and women would deliver at the hospital to receive a birth certificate; the majority of participants felt she would be treated well by health staff during this process.

- **Autonomy of refugees with disabilities in their ability to exercise SRH rights:** Mixed levels of autonomy were seen in decisions that impacted SRH, especially as it relates to pregnancy out of wedlock. Somali participants offered a range of possibilities, from parents and family members doing nothing about the pregnancy, to forcing abortion or marriage. Suggested consequences for men or boys with disabilities impregnating a woman or girl included beatings and other restrictive measures. To prevent future unplanned pregnancies, participants also cited a spectrum of possibilities, ranging from full autonomy to none around the use of family planning methods.
- **Perceptions around treatment of refugees with disabilities:** All participants agreed that violence against persons with disabilities is unacceptable. There was no disagreement or variability across or within groups in terms of perceived acceptability or unacceptability of prepared scenarios, except over early marriage. Two female participants in two groups shared concerning remarks around acceptable touching of their private body parts. All participants felt refugees with disabilities should be leaders and have equal opportunities for relationships, education and participation.
- **Safety concerns:** Among the 15 photographs of community landmarks, none were unanimously seen as a safe location by all participants. However,

the “bush” was unanimously categorized as “unsafe” by all groups and interview participants, with mentioned risks including robbery, killing, attack by wild animals, abduction and rape. The ambulance, Don Bosco Vocational Training Center, the home, Kakuma secondary school, IRC’s main hospital, reception area, the Paediatric Occupational Therapy Center and the Social Services Center were overwhelmingly seen as safe locations. Predominantly “unsafe” locations included the main road/highway, market place and water collection point, with frequent fighting over limited water mentioned in connection to the last. Caregivers shared protection concerns regarding their family members with disabilities, especially those with adolescents. Several group participants—including adolescents—were aware of post-rape care and the benefits of seeking health care after experiencing sexual violence.

- **Coping strategies, protective and facilitating factors:** Participants who were unable to leave their home in particular shared that they felt happy when they were with their primary caregiver; played with their children; received rations, new clothes or adequate treatment; or attended school. Others alluded to the importance of engaging in social networks, through taking part in social functions or receiving visits from community members, religious people and friends. Some refugees with disabilities mentioned that they could inform each other of available services and information to serve as agents for change. For the most part, however, participants offered few self-help practices and some had little self-confidence in helping themselves.
- **Recommendations from refugees with disabilities and caregivers:** Recommendations offered by refugees with disabilities to improve their SRH experience often reflected improvements in their care experience, as well as activities to empower themselves. Requests for shorter wait times can be examined in the context of the CRPD’s reasonable accommodation for persons with disabilities.

Suggestions include employing sign language and other language interpreters in health facilities; providing educational opportunities for children and adolescents; offering spaces for peer information-sharing; providing employment opportunities; and further engaging refugees with disabilities in camp decision-making.

## Key Recommendations

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

- Facilitate disability inclusion among agencies they support by providing funds for staff/provider learning opportunities; creating incentives to develop programming partnerships with agencies that have disability programming expertise; and facilitating 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 generating, vocational training 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. New programs by the United Nations High Commissioner for Refugees (UNHCR) and implementing partners should especially institute disability accommodations from their design

phase.

- 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 better address their needs and 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.
- Apply the Inter-agency Standing Committee *Guidelines on Gender-Based Violence Interventions in Humanitarian Settings* to refugees with disabilities.<sup>2</sup>
- Increase opportunities for income generation, vocational training, 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 learning opportunities for parents and caregivers about positive parenting, disability, SRH rights and gender.
- 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.

## I. Introduction

In 2012, 45.2 million people were forcibly displaced by conflict and persecution,<sup>3</sup> and 32.4 million were displaced by natural disasters.<sup>4</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>5</sup> are estimated by the World Health Organization (WHO) to comprise 15 percent of the global population,<sup>6</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, indeed, found that 22 percent of surveyed refugees live with an impairment.<sup>7</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>8</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>9</sup> Many individuals have also been subjected to forced sterilizations, abortions and marriages because of the ingrained stigmatization.<sup>10</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>11</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.<sup>12</sup> 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>13</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. Furthermore, 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>14</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>15</sup> There is, however, a lack of information about the wider SRH needs and capacities of persons with disabilities in humanitarian contexts.

Additionally, despite Article 25 (a) of the CRPD—which 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>16</sup>—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>17</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 experiences of adults and adolescents with disabilities in Kakuma refugee camp, Kenya. The study was undertaken in partnership with the International Rescue Committee (IRC).

## 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>18</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>19</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>20</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>21</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. Kenya Context

#### SRH of persons with disabilities in Kenya

In 2004, the Government of Kenya established the National Council for Persons with Disabilities (NCPWD) to implement measures intended to benefit persons with disabilities and to raise public awareness regarding such persons.<sup>22</sup> Since the establishment of the NCPWD, several local non-governmental organizations (NGOs) have been created to meet the needs of persons with disabilities. Kenya Programmes of Disabled Persons advocates on behalf of persons with disabilities in Kenya and provides HIV/AIDS education and care, microfinance programs and school fee sponsorships for adults and children with disabilities.<sup>23</sup> Northern Nomadic Disabled Persons' Organization develops networks with persons with disabilities, stakeholders in the disability world and corporations to expand and improve services for persons with disabilities.<sup>24</sup> Action Network for Disabled Youth focuses on empowerment, training and health interventions for youth with disabilities by proving employment and workplace skills, education and HIV awareness. Refugee Council Kenya raises awareness on the human rights of persons with disabilities. Women Challenged to Challenge implements consultations and follow-up trainings with providers at facilities in central and western Kenya in order to improve health services for persons with disabilities.<sup>25</sup> Despite the government's support for services for persons with disabilities, implementation is hampered by a lack of resources. As regards all health services, services for persons with disabilities, including for SRH, are weak in the Turkana region where Kakuma refugee camp is located.<sup>26</sup>

In 2008, the National Coordinating Agency for Population and Development and the Kenya National Bureau of Statistics published the results of a national survey of persons with disabilities that found that most women with disabilities are not likely to make their own choices on preferred family planning methods. Most SRH decisions are made by family members or other close relatives. These women also either lack or are not able to obtain firsthand information on SRH, HIV/AIDS and STIs.<sup>27</sup>

#### Displacement in Kakuma

Kakuma refugee camp, located in the remote north-western district of Kenya, was established in 1992 for Southern Sudanese refugees, many of whom repatriated prior to 2008. The camp stretches 13 kilometers, and at the time of the study, hosted 105,000 refugees from some 13 countries, primarily from Somalia (49%), Southern Sudan (31%), Ethiopia (6%), Democratic Republic of Congo (5%), Sudan (4%) and Burundi (3%). The camp is sub-divided into three sections and 10 zones, with approximately 100 blocks in each zone. Lutheran World Federation (LWF) is responsible for camp coordination and management. Each block comprises household members, defined as people eating from a common pot. Each block is represented by two chairpersons—one male and one female—a block leader and sectoral committees. Each sectoral committee includes representatives for nine specific issue areas: security, shelter, water, and sanitation, health, environment, child protection, gender, security and, most recently, disability. Each block is represented by zone leaders who participate in camp meetings.<sup>28</sup>

#### Situation for refugees with disabilities in Kakuma

The IRC reports that as of December 2013, there were 2,084 registered refugees with disabilities in Kakuma refugee camp among a total camp population of 128,560 persons.<sup>29</sup> This represents approximately 1.6% of the total population, which is less than typically expected. The disaggregation of data on the scope and type of impairment by age and sex was not available.

Cerebral palsy was reportedly common, as were injuries due to war trauma.<sup>30</sup>

Several agencies provide services to refugees with disabilities. IRC provides assistive devices and occupational therapy, as well as mental health, hearing and vision services.<sup>31</sup> LWF provides home-based care for refugees with disabilities who are unable to leave their homes and special needs education for children with disabilities through “open units” in schools that offer teaching in sign language and Braille. LWF has facilitated sporting events for those with hearing impairments. Refugee Council Kenya and FilmAid raise awareness of the human rights of persons with disabilities. Jesuit Refugee Service (JRS) works with both children and adults with disabilities, although it focuses primarily on children. JRS operates four day care/rehabilitation centers and offers parent training and support groups.<sup>32</sup>

IRC is the primary provider of comprehensive SRH services in Kakuma refugee camp. It provides comprehensive facility-based SRH services in four clinics and a hospital compound with a referral system to a mission hospital for surgeries. Facility-based services are supported by a community health program that employs community health promoters. SRH services include family planning; antenatal care, including to prevent-mother-to-child-transmission of HIV; delivery services; and an emergency ambulance service that covers the entire camp 24 hours per day, seven days per week, with a referral system for cesarean sections to the IRC-supported mission hospital.

### SRH and refugees with disabilities in Kakuma

In a review of literature in mid-2012, no research was found that explored SRH issues among refugees with disabilities in Kakuma refugee camp although newer assessments have examined the broader health needs of persons with disabilities in Syria and other humanitarian settings.<sup>33</sup> A consultative trip undertaken in December 2012 showed that organizations providing SRH services in the camp acknowledged a gap in the information, education and communication

(IEC) efforts for SRH initiatives to reach refugees with disabilities. Facilities did not have materials, such as large print signage directing refugees with disabilities to health facilities, or IEC materials in Braille. Providers reported depending on relatives to help with communications. Agencies were yet to systematically address disability inclusion in health services, although they were increasingly catering to the needs of refugees with disabilities by encouraging their involvement in camp block committees and including them in the promotion of equal rights for all refugees.<sup>34</sup>

## IV. Methodology

An important consideration for the WRC was to ensure maximum participation and input from various stakeholders throughout the design and implementation of the SRH and disability study. The WRC convened meetings with organizations of persons with disabilities (DPOs) and other stakeholders in Kakuma and Nairobi, to collectively develop the participatory research methodology in advance of the field assessments and select a local co-investigator (IRC). A major outcome was the establishment of an advisory group comprising DPOs, NGOs and representatives of refugees with disabilities. The Kenya advisory group is one arm of the global advisory group for the wider project that also includes representatives from Uganda and Nepal. Collectively, the advisory groups informed the development of the study design and instruments. The study was approved for implementation in Kakuma by the Kenya Medical Research Institute (KEMRI).

### 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>35</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>36</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>37</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>38</sup> timelines<sup>39</sup> and sorting<sup>40</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>41</sup> To gauge how refugees with disabilities perceived various treatment towards persons with disabilities, 25 cards were developed with pictorial scenarios and accompanying text, for participants to sort them into categories of "acceptable," "unacceptable" or mixed treatment. In order to determine safe and unsafe spaces, 15 photographs of the camp and its vicinity were taken for participants to also sort to show whether the locations or persons were seen as safe, unsafe or both. In keeping with existing guidelines and recommendations on disability inclusion,<sup>42</sup> activities were adapted with visual aids,

simple language and other modifications to enable maximum participation by refugees with different impairments.

Activities among 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 disabilities.

### IV.iii. Sampling and segmentation

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

While IRC's records of refugees with disabilities and community mobilizer knowledge of their catchment population were used to identify participants with a diversity of impairments, no official assessment was undertaken to verify or "diagnose" impairment types. 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 in experiences across the represented impairments.

Smaller group activities were convened among 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 Somali and Swahili prior to the assessment 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>43</sup> In total, 96 refugees with disabilities participated in the study, of whom 62 were women and girls, and 34 were men and boys. Seventeen caregivers and family members of refugees with disabilities were also consulted. The activities were conducted in Somali, Kiswahili, Arabic, English and Somali sign; Somali was selected as the dominant language, given the proportions of Somali-speaking refugees in Kakuma. Table 1 shows the numbers of participants ultimately consulted.

**Table 1: Number of participants consulted in Kakuma Refugee Camp**

| 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) | 41    | Swahili: 5<br>Somali: 13<br>Arabic: 5<br>English: 5                          | Somali: 4                            | Somali: 4                                      | Swahili: 1<br>Somali: 3<br>English: 1  |
| Men (20-59 years)                       | 23    | Somali: 15   | Somali: 4                            | Somali: 4                                      | N/A  |
| Adolescent girls (15-19 years)          | 20    | Somali: 12   | Somali: 4                            | N/A  | Swahili: 1<br>Somali: 1<br>Arabic: 1<br>English: 1   |
| Adolescent boys (15-19 years)           | 11    | Somali: 5  | Somali: 3                            | Somali: 3                                      | N/A  |
| Caregivers/family members               | 17    |  |                                      |  |  |

*\* Although not included in the final count, one Somali woman's transcript was excluded from the study since the study team later learned that she was over 50 years of age.*

#### IV.iv. Participant recruitment

Refugees with disabilities were recruited through contact lists managed by IRC and IRC's community health mobilizers, as well as snowball sampling from identified contacts. Community mobilizers were requested to identify participants from their respective blocks to ensure wide coverage within Kakuma I, II and III.

As part of participant recruitment and in advance of study implementation, community mobilizers made home visits to explain the purpose of the study, expectations for participation and use of findings. They also clarified any questions to prevent misunderstanding. Fact sheets written in Somali, Kiswahili, Arabic and English were disseminated at this time.

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

IRC recruited 12 refugee data collectors and Somali sign interpreters who worked in the camp. 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.) in Somali and Kiswahili 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, note takers and sign interpreters.

#### IV.vi. Informed consent

Informed written consent was sought from all refugees with disabilities in their local language and tailored to accommodate different impairments. Languages for consent included Somali, Kiswahili, Arabic, English and Somali 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, and that their ability to access services was not contingent upon participation. Consent processes were conducted immediately before the activity. Only those participants who consented were permitted to join the activity.

To ensure adequate understanding of their involvement in the activities, the consent/assent process for participants was interactive. As applied in other SRH-related studies,<sup>44</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?
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. For those with intellectual impairments, if they expressed interest to participate but answered questions incorrectly, the protocol sought caregiver/family member permission.

Per Kenyan law, minors (15-17 years) were asked to

provide written assent, and a parent/guardian was asked to provide written permission. Pregnant girls, those who have children or those who were married or living on their own were determined eligible to provide their own consent.

Per KEMRI’s request, any participant who did not wish to participate in the study was also requested to sign the consent form indicating their refusal. All participants were reminded that refusal to participate would not influence their ability to access services. In the Kakuma study, no participant declined participation.

Caregivers/family members who participated in activities were also asked to provide written consent immediately prior to the start of the activity.

#### 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 IRC’s own services as well as an existing network of partner organizations.

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, time lines and other posters developed during participatory exercises were photographed for translation and data analysis. IRC collected the data collectors’ handwritten notes at the end of data collection activities. Typed transcripts were made available only to WRC 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 IRC, 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. WRC further facilitated a discussion among the team on their views and analysis at the end of data collection.

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 sorting 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 adolescents with intellectual impairments and those with mental impairments. IRC's lists were most comprehensive for those with physical and sensory impairments. Additionally, those with mild intellectual disabilities were often hidden from public view, making their identification challenging. Analysis thus focused on general and common findings across refugees with disabilities rather than attempting to solicit saturation by impairment group.

Four group activities were undertaken in sign language. While both sign interpreters attended the data collector training, one sign interpreter noted that he was unsure whether participants in one men's group understood the sign correctly, especially where the language pertained to SRH. The obtained information was contextualized, however, and only reported where some level of certainty could be assured.

Participant recruitment and data collection were undertaken in part by IRC staff. This may have impacted

participant responses, especially towards social desirability bias. The team was trained to maintain a neutral and encouraging environment, however.

The study employed facilitated translation techniques where transcription was conducted immediately after the activity on the same afternoon with the facilitator, note taker and transcriber.<sup>45</sup> This minimized recall bias and translation error; however, the possibility of omitted information exists, especially where time was constrained during the transcription process.

## V. Findings

### V.i. Overarching concerns

Long wait times to services and lack of disability accommodations during food and non-food item distributions were raised as general challenges for refugees with disabilities. Many voiced similar concerns as a Somali woman in a group of participants with intellectual impairments, who felt, "They cannot queue the line like other people."<sup>46</sup>

Other concerns included limited disability services in the camp, especially for adults, as well as interest in receiving more assistive devices. An English-speaking woman in a group of participants with physical impairments explained the consequences: "Within the camp there is no prosthetic repair—you have to find a way to get your own prosthetic to Nairobi to get it repaired. And, this delay can cause you to lose your job if you are working and it makes you immobile for a very long time."<sup>47</sup>

Several refugees with disabilities and caregivers also mentioned their interest in resettlement. Among them, a common theme was their belief that persons with disabilities should have priority in the resettlement processes.

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

Both adolescent and adult participants frequently listed IRC and FilmAid as agencies that provide information about SRH to refugees with disabilities, while others mentioned the National Council of Churches of Kenya and JRS. Group participants shared that they receive information from notice boards, megaphones, videos and community health workers/promoters. Others listed special seminars, community leaders, schools and doctors.

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, women and girls demonstrated more awareness of female organs and their functions than of male organs and their functions. The reverse was the case with men and boys. Adolescents with disabilities who attended school seemed to know more than adults about the reproductive organs and their functions. Among those with hearing impairments, Somali adolescent girls had been taught about SRH in school, and could hence identify the organs and functions. Participants with intellectual impairments had difficulty identifying and locating body parts, and were generally less aware about their functions.

Most group participants were aware of HIV, although knowledge of STIs varied across groups. Boys and men appeared to know less about STIs than girls and women, who could cite one or two symptoms. This trend was similarly observed among groups that used sign language. While all participants in one group of Somali refugees with intellectual impairments had heard of HIV, only one participant among the three groups of refugees with intellectual impairments was familiar with STIs. Among participants who were unable to leave their homes, four of eight had been informed of HIV as well as STIs, noting syphilis and gonorrhoea as examples. One Arabic-speaking adolescent girl and a Somali woman stated that they were not familiar with HIV or STIs.

To prevent pregnancy, group participants most often cited short-term methods (condoms, pills and injectables), followed by long-acting methods (intrauterine devices and implants). Groups of signing participants also demonstrated familiarity with short-term methods, noting that they had been taught in school. Adolescent group participants only mentioned short-term methods. Only two participants among the three groups of Somali refugees with mild intellectual impairments appeared to be familiar with contraceptives. Among refugees who were unable to leave their homes, those who were familiar with HIV and STIs had heard of at least one contraceptive method (including condoms). Male and female sterilization was not raised as a method to prevent pregnancy by any participant.

Despite general awareness of short-term methods, some misconceptions were voiced. A handful of women with disabilities feared that condoms could get stuck inside a woman's body if they burst, could cause cancer or could make a woman lose her fertility. Somali adult women especially noted that use of family planning was not encouraged by religious teaching.

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

A sizeable number of refugees with disabilities and caregivers shared that they were satisfied with existing health services in the camp. For example, Somali adolescent boys, one signing and another with a mild intellectual impairment said: "The health services in the camp are great. They give you high quality treatment and medicine because they are scared to give you the wrong medicine and you die"<sup>48</sup> and "There are no barriers because everything is easier in the camp. Hospital is free and the ambulance is always there,"<sup>49</sup> respectively. A Swahili-speaking caregiver likewise mentioned that most of the time, "They receive good care and are treated equally like any other person."<sup>50</sup>

A larger number of refugees with disabilities and their caregivers, however, complained about challenges in accessing services, as well as limited, specialized care for their particular needs. Long wait times were

voiced as a concern by many groups of refugees across displacement types and languages: “When you are disabled, accessing the health center is difficult. If your device is broken—for example, your crutch—it takes too long for it to be replaced.”<sup>51</sup> For those with physical impairments, transport to the health facilities was raised as an additional challenge.

Language barriers, both in terms of the diversity of languages spoken in the camp, as well as the lack of sign interpreters, were also raised by several groups of participants. For example, a Somali adolescent girl with a physical impairment said: “Language is a big challenge. It is hard to communicate with the people at the health centers, and it is also very hard to get there.”<sup>52</sup> Among those who signed, one Somali man said: “Sign language will be a challenge. Sometimes, they [health staff] give you medicine for vomiting because they think you have malaria, because the doctors don’t know sign language. So they have to guess.”<sup>53</sup> A male signing participant felt: “Hearing impaired are oppressed when they are in the queue. No one cares for them and they are always neglected.”<sup>54</sup>

For Somali women with disabilities, the sex of the health provider appeared to impact their confidence and ability to speak about SRH, including pregnancy-related concerns. This concern was seemingly unrelated to disability status, however.

In addition to environmental and structural barriers, several groups of refugees with disabilities and caregivers identified attitudinal barriers. Several groups and individuals mentioned discrimination, vis-à-vis provider attitudes, as well as preferential treatment of those related to service providers, as a concern. One Somali caregiver explained: “In hospitals, we face a lot of pressure. They [health providers] belittle us because we have disabled patients.”<sup>55</sup> Adolescent boys with disabilities and caregivers further lamented inequitable services. They said: “The staff always serve people they know”<sup>56</sup> and “The health workers are corrupted. They don’t consider the needs of our children, the disabled person.”<sup>57</sup> While not widespread, a handful of participants remarked, “There is a high rate of neglect.”<sup>58</sup>

No participant mentioned that there was a lack of service points to receive SRH information and services; accessibility of existing resources appeared the greater challenge.

#### V.iv. Experiences around romantic relationships

Participants treated questions around adolescents with disabilities having romantic relationships as natural in 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. Feedback varied regarding the acceptability of relationships; Somali adolescents often mentioned that some parents would reject the relationship and prefer that the child focus on completing her education instead.

Where adolescents were engaged in relationships, the most popular method to prevent pregnancy was abstinence, especially among adolescents. A noticeable remark from Somali group participants was, “Sex before marriage shouldn’t be allowed because it is prohibited by religion.”<sup>59</sup> Several groups across languages, however, mentioned that the adolescents could potentially use short-term contraception.

In terms of health information and advice, those with physical, mild mental and hearing impairments listed parents, friends, relatives, teachers, neighbors, religious leaders, churches/mosques, doctors, the IRC clinic, FilmAid and community health workers/promoters as sources of information. Parents were more often mentioned in the context of advice around pregnancy prevention, while health workers were often mentioned in relation to information regarding STI prevention. A Swahili-speaking woman with a physical impairment felt, “The parents should be the ones to advise, but even the neighbors, teachers and other relatives should advise because sometimes, as a parent, one does not know what the child is doing until [one] hears it from somebody else after it has happened.”<sup>60</sup>

Those with mild intellectual impairments offered more mixed responses; some felt that no one would advise,

while Somali adolescent boys stated: “No one from the family or neighbor would advise him or her about relationships. [Instead] friends and relatives would advise.”<sup>61</sup> One man communicating in sign language further cautioned, “No one would advise him because of language problem and sometimes, if you get someone who signs and you share about STI/HIV/AIDS, they will spread rumors about you.”<sup>62</sup>

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

Several groups of refugees with disabilities felt that if a girl or woman with disabilities becomes pregnant, “Some will wonder how she got pregnant [when] she is disabled,”<sup>63</sup> or, she will be seen as “...not capable to raise a child, and people will say bad things about her.”<sup>64</sup> However, consensus among groups across languages, sex, age and impairment category was that if a girl or woman with disabilities became pregnant, her marital status would be the key determinant of how she would be treated by her family and neighbors. If she were married, the pregnancy would be accepted. “If she is married, the family would be happy; if she is not married, they would not be happy,”<sup>65</sup> was a frequent response.

On the other hand, if the girl or woman with disabilities was not married, participants across all segmented categories agreed that she would face social stigma. The family and neighbors would say, “She is a prostitute; others say she brought a burden to the family.”<sup>66</sup> Additionally, English-speaking women with physical impairments suggested: “Her family and neighbors may think badly because they cannot think the disabled girl can get pregnant. They may blame the mother for not taking care of the girl and messing up.”<sup>67</sup> No participant viewed the pregnancy as a result of a romantic or equitable relationship.

Indeed, in terms of real experiences, when people around her discovered her pregnancy, a Somali new mother noted: “Family and neighbors said [I] could not give birth. And the neighbor said, ‘A disabled woman cannot take pregnancy.’”<sup>68</sup>

For unmarried girls and women who find themselves pregnant, participants offered a range of possibilities, including: run away from home; keep the pregnancy; abort the pregnancy; be forced to abort by parents, family or the baby’s father; be forced to marry; or choose to marry the baby’s father and raise the child together. Responses were mixed across and within groups. For girls and women that choose to keep the pregnancy, several groups mentioned they would receive good nutrition and would be cared for by her family and friends, or agencies such as IRC and Save the Children. Somali women with physical impairments agreed, “She will be cared for by her parents, even if they are unhappy.”<sup>69</sup>

When a pregnant girl or woman with disabilities is ready to deliver her baby, participants noted she would do so at the hospital, most likely through use of an ambulance, so that the baby can receive a birth certificate. Fewer participants suggested she would use a taxi or walk to the hospital. Common responses to accompaniment during the birthing process were the girl/woman’s family, neighbor, friends and the baby’s father.

Once she arrives at the health facility, most participants agreed that she would be treated nicely and with respect by health providers. Somali adolescent boys with physical impairments felt, “She will receive special treatment...the doctors will feel sympathy and give her special care.”<sup>70</sup> Somali women with intellectual impairments agreed, “They will be treated normally like any other person.”<sup>71</sup> Even participants who complained of maltreatment at health facilities generally agreed that a pregnant woman or girl with disabilities would be treated well during her delivery process. Only a handful of participants felt otherwise; a few Somali adolescent girls shared that, “They [health providers] will look down upon us because we are disabled,”<sup>72</sup> or that health providers “are harsh” with them.<sup>73</sup>

In terms of communicating with health staff, two of four signing groups added, “It is going to be hard because they [health providers] don’t know sign language, and it will be worse if she [pregnant girl/woman] can’t write anything.”<sup>74</sup> On the other hand, signing adolescent boys felt that “[communications] will be straightforward

because doctors will use gestures to communicate; if parents are with her, they will communicate with the doctor.”<sup>75</sup>

The Somali new mother provided some helpful advice to her peers in similar situations: “It is normal to get pregnant and give birth, and they [other women with disabilities] should not be afraid. The children will help her in the future so [she] should raise the children well... Disabled women should be confident of themselves, just like a normal woman.”<sup>76</sup>

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

Feedback from refugees with disabilities who were unable to leave their homes and caregivers showed that decisions related to health visits or medicines for common and minor illnesses were made by caregivers and health providers, often with their child’s or family members’ involvement. Several caregivers stated that forcing treatment would only harm or hurt the child.<sup>77</sup>

Mixed levels of autonomy were seen in decisions that impacted SRH, especially as it relates to pregnancy out of wedlock. As mentioned above, Somali participants offered a range of possibilities, from parents and family members doing nothing about the pregnancy to forcing abortion or marriage. Male participants in particular asserted that parents would “take her to a Kenyan hospital to abort the child,”<sup>78</sup> or “they would assign someone else to marry her.”<sup>79</sup> Even adolescents felt that “they [parents] can marry the girl off to a relative so she can’t have a pregnancy outside marriage again.”<sup>80</sup> A Somali signing woman, however, offered more middle ground: “Not all people are the same. Some parents would end the pregnancy and would not allow her to get pregnant in the near future, but some parents would allow her to keep it.”<sup>81</sup>

The ability of a boy or man with disabilities to impregnate a girl or woman was seen with concern by several groups: “They [the parents] will abuse or even try to kill him when it comes to the girl’s family”<sup>82</sup> and “In some communities, the boy will be beaten as a punishment

for his mistake and to serve as a lesson to the other boys.”<sup>83</sup> Beatings were mentioned on several occasions, including from adolescent boys. More moderate consequences were suggested by women with intellectual impairments, with comments such as: “They can advise the boy, but they can’t do anything if he doesn’t listen.”<sup>84</sup> Only Somali men in a group of participants with physical and mental impairments offered a positive remark: “They [family] are going to be happy because a disabled man made a girl pregnant, especially the disabled man’s family.”<sup>85</sup>

To prevent future unplanned pregnancies, participants cited a spectrum of possibilities, ranging from full autonomy to none. Somali adolescents felt that “the woman can decide for herself. It is a partner decision—the man and the woman together”<sup>86</sup> and “if she is married, they both decide. If not married, she would decide herself.”<sup>87</sup> Several English-speaking adults concurred with this thinking. Others felt family members may be involved in the decision-making process, but leave the final decision to their child. For example, a Somali signing adolescent girl suggested, “They [parents] would advise her on how not to get pregnant, but they will not prevent her,”<sup>88</sup> while a Somali woman in a group of participants with intellectual impairments said: “They would not prevent her from pregnancy. They cannot prevent someone. They can only advise.”<sup>89</sup>

Despite some suggestive liberal thinking, participants across languages, age and sex also voiced more restrictive consequences. For example, Arabic- and Somali-speaking female participants suggested, “The parents will take her to hospital and tell the clinicians to give her any family planning method to avoid her becoming pregnant again with or without her consent,”<sup>90</sup> or, “They will give her injection. The girl or woman may not agree, but her parents will make her,”<sup>91</sup> respectively. An English-speaking woman with an intellectual impairment added, “Parents are the ones that suffer to take the girls so they should decide if she should use family planning.”<sup>92</sup> Somali adolescent boys with mild intellectual impairments additionally suggested that “she will be locked in the house”<sup>93</sup> and “she might be circumcised again.”<sup>94</sup> Such feedback suggests limited autonomy in SRH

decision-making for unmarried women and adolescent girls with disabilities in particular.

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

All participants agreed that violence against persons with disabilities is unacceptable. Twenty-five scenarios were presented to group activity participants to classify as “acceptable,” “unacceptable” or possibly both. Six images were of positive scenarios, including “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.” All groups sorted these as “acceptable;” all participants felt refugees with

disabilities should be leaders and have equal opportunities for relationships, education and participation. There was hence no disagreement or variability across or within groups in terms of perceived acceptability of these scenarios.

Of the remaining 19 images, all but one was deemed “unacceptable” by participants. The only scenario that received a mixed response was “early marriage.” Somali women of reproductive age with physical impairments were divided within their group, while Somali adolescent boys with intellectual impairments agreed that early marriage was acceptable. Otherwise, the remaining 13 groups to which this scenario was presented agreed that it was “unacceptable” for refugees with disabilities to undergo early marriage. See Table 2 for more information.

| Acceptable   | Unacceptable  | Mixed Responses  |
|--|---|--|
| <ul style="list-style-type: none"> <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>• A person with disabilities as a leader of a community</li> </ul> | <ul style="list-style-type: none"> <li>• Rape of an adult</li> <li>• Rape of a child</li> <li>• Sexual harassment</li> <li>• Sexual exploitation and abuse</li> <li>• Forced prostitution</li> <li>• Beating of an adult with a disability by a family member</li> <li>• Beating of a child with a disability</li> <li>• Neglect</li> <li>• Forcing a person with disabilities to be sterilized</li> <li>• Denying access to services</li> <li>• Child labor</li> <li>• Controlling money</li> <li>• Not allowing opportunity</li> <li>• Non-payment or low pay for work</li> <li>• Female genital cutting</li> <li>• Promoting traditional or cultural myths about person with disabilities</li> </ul> | <ul style="list-style-type: none"> <li>• Early marriage</li> </ul> |

While the degree of acceptable touching was probed to some degree, the study team heard remarks from participants in two groups that caused concern. One woman in a group of Arabic-speaking women of reproductive age noted that she would allow anybody to, “Touch their private parts.”<sup>95</sup> One 16-year-old Somali adolescent girl in a group of participants with physical impairments also stated, “It is play if a person can touch you anywhere.”<sup>96</sup> When probed by the data collectors, it appeared the girl had been raised to believe this way.

### V.viii. Safety concerns

Responses to questions around safety yielded interesting findings. Among the 15 photographs of community landmarks, none were unanimously seen as a safe location by all participants. However, the “bush” was unanimously categorized as “unsafe” by all groups and interview participants. Group participants said: “[The] bush is dangerous because you can be robbed or killed,”<sup>97</sup> “You may be attacked or wild animals can kill you”<sup>98</sup> and “You can be abducted and raped.”<sup>99</sup> Across groups and interviews, common remarks were “If anyone harms you, no one can see you”<sup>100</sup> and “There is nobody to help you if someone will attack you.”<sup>101</sup>

The remaining 14 photographs received mixed responses from participants regarding their designation as safe or unsafe. See Table 3 for more information regarding variability across activities. On the whole, variability was seen across groups for some locations, while less variability was observed within groups (see Table 4). Few noteworthy differences were seen across sex and age groups.

The ambulance, Don Bosco Vocational Training Center, the home, Kakuma secondary school, IRC’s main hospital, reception area, the Paediatric Occupational Therapy Center and the Social Services Center were overwhelmingly seen as safe locations, although several groups of participants were not aware of the latter two locations. Among these, all but one interviewed participant felt the IRC’s main hospital was safe. Common responses were “People are treated well [at the main hospital]”<sup>102</sup> and they are given treat-

ment. The English-speaking 20-year-old woman with multiple impairments who provided the mixed response shared, “I feel safe when I get a medical assistant who can listen to my problems, but I am not safe when I get a medical assistant who does not want to listen to anything about me.”<sup>103</sup>

The ambulance was categorized as safe by all but three groups, with similar reasoning to care provided at the main hospital. Groups that felt it unsafe or both—such as Somali signing women—said: “When you are sick it brings you to the hospital. If you cannot hear the sound for emergencies, you will be knocked [down].”<sup>104</sup>

The Don Bosco Vocational Training Center was seen as a safe location by all groups and all but one interview participant who nuanced safety as contingent upon the availability of security. Adolescent girls in a group with hearing and speech impairments agreed, “[Don Bosco] is a learning center and always has people.”<sup>105</sup> On the whole, where there was security (gates and guards), such as at the LWF compound, participants saw the location as safer than where there was not.

Regarding Kakuma secondary school, while roughly half of 26 groups and interviewed individuals felt that it was safe, mixed feedback included: “It depends on the type of disability. If you have a cycle, it needs a lot of space, so [we] can’t register in school. It is [however], safe for people who can sit at a desk.”<sup>106</sup> Similar accessibility issues were mentioned by an individual who was unable to leave her home: “My legs are paralyzed, which doesn’t allow me to move from home to school, and I am squished with my fellow students at the same desk.”<sup>107</sup>

The home was primarily seen as safe, aside from five groups and one individual that felt it was both or unsafe. Common reasons for limited safety, particularly from those who signed were: “It is safe because you get shelter there, but it is unsafe if a thief enters the house. You will not hear anything.”<sup>108</sup> For most of those who were unable to leave their homes, the home was seen as a safe place, with several noting that they felt safe when they were with their mother or other family members.

Table 3: Variability in safety categories across activities

| Safe | Unsafe   | Mixed Responses  |
|------|--|--|
|      | <ul style="list-style-type: none"> <li>• Bush</li> </ul> | <ul style="list-style-type: none"> <li>• Ambulance</li> <li>• Don Bosco Vocational Training Centre</li> <li>• Home</li> <li>• Kakuma Secondary School</li> <li>• Latrine</li> <li>• LWF compound</li> <li>• Main hospital (IRC)</li> <li>• Main road/highway</li> <li>• Market</li> <li>• Paediatric Occupational Therapy Centre</li> <li>• Police post</li> <li>• Reception area (refugee registration center)</li> <li>• Social Services Centre</li> <li>• Water collection point</li> </ul> |

As for the reception center, all groups categorized it as a safe location, while three participants consulted for individual interviews (those who were unable to leave their homes) felt it unsafe. The rationale was less associated with physical safety and included: “Food cooked there is bad for human consumption. Maize and beans caused diarrhea. The place is also congested and dirty.”<sup>109</sup>

Few negative comments were received regarding the Social Services Center. However, one English-speaking women with multiple impairments shared: “The staff there have discrimination. I was there one day to receive my NFI [non-food item], but due to not being related to the staff working there, I was told the items were finished. Yet, I was seeing some packed through the window in the store.”<sup>110</sup>

In terms of predominantly “unsafe” locations, in addition to the bush, the main road/highway, market place and

water collection point were identified. The possibility of accidents was mentioned in relation to the main road/highway, with concerns such as “[The] highway is always dangerous because a car can knock you”<sup>111</sup> and “You cannot hear and you will be knocked.”<sup>112</sup> Only Somali adolescent boys in the group communicating in sign felt the road to be safe. The water collection point was equally seen as an unsafe location, with the same Somali group feeling otherwise. The most common reason for the lack of safety was related to the frequency of fighting over scarce resources: “Many people go there. Sometimes, there is a shortage of water and people fight.”<sup>113</sup> Others noted accessibility challenges: “If you are blind you can fall over all of the water jugs sitting around the tap; if you are deaf you don’t know what others are saying about the water situation. So you just stand there”;<sup>114</sup> “I am not able to go fetch water and there is a pool of water and I might fall”;<sup>115</sup> and “If you meet people who are not compassionate, they can even chase you instead of help you get water.”<sup>116</sup>

| Safe  | Unsafe  | Mixed Responses   |
|---|---|---|
| <ul style="list-style-type: none"> <li>• <b>Ambulance</b></li> <li>• <b>Don Bosco Vocational Training Centre</b></li> <li>• <b>Home</b></li> <li>• <b>Kakuma Secondary School</b></li> <li>• <b>Latrine</b></li> <li>• LWF compound</li> <li>• <b>Main hospital (IRC)</b></li> <li>• Main road/highway</li> <li>• Market</li> <li>• <b>Paediatric Occupational Therapy Centre</b></li> <li>• Police post</li> <li>• <b>Reception area</b> (refugee registration center)</li> <li>• <b>Social Services Centre</b></li> <li>• Water collection point</li> </ul> | <ul style="list-style-type: none"> <li>• Ambulance</li> <li>• <b>Bush</b></li> <li>• Home</li> <li>• Kakuma Secondary School</li> <li>• Latrine</li> <li>• LWF compound</li> <li>• <b>Main road/highway</b></li> <li>• <b>Market</b></li> <li>• Paediatric Occupational Therapy Centre</li> <li>• Police post</li> <li>• Reception area (refugee registration center)</li> <li>• Social Services Centre</li> <li>• <b>Water collection point</b></li> </ul> | <ul style="list-style-type: none"> <li>• Ambulance</li> <li>• Don Bosco Vocational Training Centre</li> <li>• Home</li> <li>• Kakuma Secondary School</li> <li>• Latrine</li> <li>• Main hospital (IRC)</li> <li>• Market</li> <li>• Police post</li> </ul> |
| <p>* <i>Bold font indicates that the majority of groups and interview participants selected the photograph as “safe” or “unsafe.”</i></p>   |   |   |

Despite the majority of groups and individuals describing the market as unsafe, a handful of groups and individuals felt it safe or both safe and unsafe. The level of crowdedness was seen as both positive and negative: “Because so many people are there, if someone attacks you, you will have someone to help you,”<sup>117</sup> while another woman who was unable to leave her home noted, “I cannot move alone in the congested and crowded environment where property can be stolen.”<sup>118</sup> Somali adult women further stated, “Someone who is deaf cannot hear the sound of the car or vehicle and can be knocked.”<sup>119</sup> A deaf woman was, indeed, knocked down by a motorbike that had come from behind.

The latrine was a contentious location, as feedback was less consistent across groups. Those who felt it unsafe reported, “A person can come and rape you

there.”<sup>120</sup> A signing Somali adolescent boy offered more nuanced feedback: “It is safe if it has a lock inside. It is unsafe when it doesn’t have a lock and someone can rape you.”<sup>121</sup> An English-speaking woman in a physical impairment group noted: “Latrines are also safe and unsafe depending on the disability you have. If your legs are fine, it is not a problem, but if you have a problem with your lower extremities, then the type of latrines we have in the community are unsafe.”<sup>122</sup>

Additional safety concerns were raised by participants who were home-based, one of whom noted, “Outside the house, maybe when I go to my neighbors, I don’t feel safe because some people look down upon me because I am disabled.”<sup>123</sup> Somali men and adolescent boys with physical impairments said the food distribution center was unsafe, given the lack of an accessible corridor. During the study activities, one participant

disclosed a past incident of sexual violence, although the incident took place many years ago in Somalia.

When asked whether safety concerns differed for girls versus boys, adolescent groups often noted physical differences between the two sexes. A group of Somali adolescent girls with physical impairments agreed: “In the bushes, a boy can go there and live, but girls are scared of being raped. Boys are more muscular than girls so they can fight back.”<sup>124</sup> A Somali woman with a mild intellectual impairment felt, “Girls are ready meat and anyone could attack you.”<sup>125</sup> Adolescents especially pointed to the ability of boys to fight back.

Caregivers shared protection concerns regarding family members, especially adolescent girls with disabilities. In discussions of the differences between having girls and boys with disabilities in the family, as well as accompanying safety risks as the child matures, caregivers said, “With boys, they can only have STIs and HIV, but with girls, they can have these diseases as well as become pregnant.”<sup>126</sup> Similarly: “For a girl to have a relationship with a boy, there will be risk for the girl to get pregnant and the man could abandon her with the child. He could also transmit diseases to her if he is infected.”<sup>127</sup>

Despite safety concerns, several group participants—including adolescents—were aware of post-rape care and the benefits of seeking health care after experiencing sexual violence. For example, Somali adolescent girls with physical impairments noted, “If the girl has been raped, [she] will go to the hospital and get treatment to prevent unwanted pregnancy, treatment of STIs and to prevent HIV.”<sup>128</sup> They appeared to have received this information from community campaigns and messaging.

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

Participants who were unable to leave their homes in particular described seemingly protective factors in their lives, especially those who gave them emotional respite. Many noted that they felt happy when they

were with their primary caregiver or they could play with other children. Others agreed that they felt happy when they could receive rations, new clothes or adequate treatment. Adolescent girls voiced opportunities to go to school; one 19-year-old English-speaking girl with a physical disability shared that she was happy to pass her exams for class 7. Three adults and adolescents further hinted at the importance of engaging their social networks. And an English-speaking 20-year-old woman with multiple impairments said that she is a choir member and is happy when she attends church service to see other people sing. While she is not able to capture the song easily, she likes to watch other people.<sup>129</sup> Others mentioned that they have “peace of mind” when community members, religious persons or friends visit and pray for them at their home or give them hope in life.<sup>130, 131</sup>

When participants were asked what they could do to serve as agents for change, those who made suggestions mentioned that they could inform each other of available services and information. One Somali girl in a group of adolescents with physical impairments noted: “Persons with disabilities can inform those who are not informed. Persons with disabilities are different from each other so one person can help another.”<sup>132</sup> Caregivers further shared, “When someone is sick in a room and you go over to them and talk to them and listen to them, you help them.”<sup>133</sup> For the most part, however, participants offered few self-help practices and some had little self-confidence in helping 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. These included:

- Provide fast-track options to good quality health and counseling services, so that they do not need to wait in a long queue.
- Provide assistive devices and community-based physiotherapy more readily, as well as other finan-

cial assistance and non-food items (e.g., clothing) to refugees with disabilities.

- Ensure language interpreters, including those for sign language, are present at hospitals and clinics.
- Reduce the rate of corruption in the camp so that aid is not dependent on whom one knows.
- Increase the amount of information shared about existing services (including SRH), through seminars, training and use of the television.
- Increase outreach to refugees with disabilities who are isolated in their homes, so that they have more exposure and can receive additional support and assistance.
- Improve the way chronic illnesses are treated so that more than paracetamol (acetaminophen) can be received.
- Further engage refugees with disabilities in camp decision-making.
- Offer more educational opportunities for children and adolescents with more serious impairments, where they can feel at ease and caregivers do not feel that they are burdening the teacher. One Somali man with a physical disability noted: “We need schools for the disabled. We are physically disabled, but not disabled in our soul.”<sup>134</sup>
- Create spaces where refugees with disabilities can educate each other.
- Provide employment opportunities for refugees with disabilities and caregivers, so that they have the opportunity to earn an income.

## VI. Key Considerations

This study among Somali-, Arabic-, Swahili- and English-speaking and Somali-signing refugee women, men and adolescents with disabilities showed a wide range and mix of findings. Examining the findings in the context of

the study, several observations can be made:

1. **Higher awareness levels regarding SRH topics and post-rape care among some refugees with disabilities demonstrate the positive impact of existing awareness-raising efforts by service delivery agencies to date, and calls for their further amplification.** School-going adolescents and signing participants, in particular, were familiar with SRH topics such as the reproductive anatomy, HIV/STIs and family planning methods. Even some refugees with disabilities who were home-based had received SRH information through health care providers and seminars. Strengthening outreach to those with intellectual impairments and actively reaching out to refugees with disabilities who are unable to leave their homes can decrease the awareness gap between refugees with different types of impairments and increase opportunities for the latter group, in particular, to receive information from external sources.
2. **While all consulted refugees with disabilities agreed in principle that violence against persons with disabilities—including forced sterilization—was unacceptable, participants suggested varying degrees of autonomy and SRH decision-making for unmarried women and adolescent girls with disabilities who became pregnant, showing discrepancies between theory and practice.** Across sex, age, language and impairment type, the discrepancies in responses between the timeline activity and sorting of scenario cards show that unmarried refugees with disabilities may find challenges to realizing their SRH rights. The lack of mention of equitable, romantic relationships shows that even among refugees with disabilities, this concept is uncommon.
3. **Protective factors in the community can be enhanced by increasing social engagement and engaging social networks, especially for those who are isolated in their homes.** While physical and sexual risk factors prevail for refugees with disabilities in the camp, participants who

were unable to leave their homes, in particular, mentioned protective resources, especially persons and activities that offered emotional and mental respite. Increasing their engagement in social functions—as well as their contact with safe, social networks—can enhance their protection as well as increase outlets for information-sharing around SRH.

4. **Recommendations offered by refugees with disabilities to improve their SRH experience often reflected improvements in their care, as well as activities to empower themselves.** Employing interpreters—sign and other languages—and providing equitable services were mentioned as practical ways to improve provider-client interactions and service experiences. Requests for shorter wait times can further be examined in the context of the CRPD's reasonable accommodation for persons with disabilities. Refugees with disabilities also provided ways that they themselves could overcome challenges, especially with educational opportunities for children and adolescents, spaces for peer information-sharing,

employment opportunities and further engagement in camp decision-making.

## VII. Conclusion

This study among refugees with a variety of impairments is one of three studies that explored the intersections between SRH and disabilities 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 Kakuma, as well as in other humanitarian settings more broadly. Targeted outreach and emphasis to meet the SRH needs of refugees with disabilities in Kakuma can better realize the rights of this vulnerable, but resilient group.

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



The market was seen as both safe and unsafe by participants.

## 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://wrc.ms/N8o9CH>
2. IASC. 2005. *Guidelines on Gender-Based Violence Interventions in Humanitarian Settings*. [http://www.humanitarianinfo.org/iasc/page-loader.aspx?page=content-subsi-tf\\_gender-gbv](http://www.humanitarianinfo.org/iasc/page-loader.aspx?page=content-subsi-tf_gender-gbv).
3. UNHCR. 2013. *Displacement: The New 21st Century Challenge: UNHCR Global Trends 2012*. <http://www.unhcr.org/51bacb0f9.html>.
4. IDMC. 2013. *Global Estimates 2012: People displaced by disasters*. <http://www.internal-displacement.org/natural-disasters>.
5. UN. 1996. Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/convention/conventionfull.shtml>.
6. WHO. 2011. *World Report on Disability*. [http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html).
7. HelpAge International and Handicap International. 2014. *Hidden victims of the Syrian crisis: disabled, injured and older refugees*. <https://data.unhcr.org/syrianrefugees/download.php?id=5812>.
8. Stephanie Ortoleva and Hope Lewis. 2012. *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://usicd.org/index.cfm/news\\_forbidden-sisters-a-report-on-violence-against-women-with-disabilities-an-overview-of-its-nature-scope-causes-and-consequences](http://usicd.org/index.cfm/news_forbidden-sisters-a-report-on-violence-against-women-with-disabilities-an-overview-of-its-nature-scope-causes-and-consequences).
9. Lena Morgon Banks & Sarah Polack. 2014. *The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities Evidence from Low and Middle Income Countries*, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine. <http://disabilitycentre.lshhtm.ac.uk/files/2014/07/Costs-of-Exclusion-and-Gains-of-Inclusion-Report.pdf>.
10. WHO/UNFPA. 2009. *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*. [http://www.unfpa.org/webdav/site/global/shared/documents/publications/2009/srh\\_for\\_disabilities.pdf](http://www.unfpa.org/webdav/site/global/shared/documents/publications/2009/srh_for_disabilities.pdf).
11. UN General Assembly, 67th Session, *Report of the Special Rapporteur on violence against women, its causes and consequences*, A/67/227, August 3, 2012, <http://www.ohchr.org/Documents/Issues/Women/A.67.227.pdf>, last accessed November 2, 2012. See also, Human Rights Council, 20th Session, *Thematic study of the issue of violence against women and girls with disabilities*, A/HRC/20/5, March 30, 2012, [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-5\\_en.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-5_en.pdf), last accessed November 2, 2012.
12. WRC. 2008. *Disabilities among Refugees and Conflict-affected Populations*. <http://www.womensrefugeecommission.org/resources/download/609>.
13. Ibid.
14. WRC. 2014. *Disability inclusion: Translating policy into practice in humanitarian action*. <http://www.womensrefugeecommission.org/programs/disabilities/disability-inclusion>.
15. WRC. 2013. *Building capacity for disability inclusion in GBV programming in humanitarian settings: My'Ani refugee camp, Ethiopia*. <http://www.womensrefugeecommission.org/programs/disabilities/research-and-resources/download/969>.
16. UN. 1996. "Article 25 (a)," Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/convention/conventionfull.shtml>.
17. IAWG on RH in Crises. 2010. *Inter-agency Field Manual on Reproductive Health in Humanitarian Settings*. <http://iawg.net/resources2013/tools-and-guidelines/field-manual/>.
18. UN. 1996. "Article 1," Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/convention/conventionfull.shtml>.
19. UN. 1996. "Preamble," Convention on the Rights of Persons with Disabilities.
20. CBM. 2012. *Inclusion Made Easy*, p. 3. [http://www.cbm.org/article/downloads/78851/CBM Inclusion Made Easy - complete guide.pdf](http://www.cbm.org/article/downloads/78851/CBM%20Inclusion%20Made%20Easy%20-%20complete%20guide.pdf).
21. ICPD. 1994. Programme of Action. A/CONF.171/13/Rev.1 -- *Report of the International Conference on Population and Development*. <https://www.unfpa.org/public/global/publications/pid/1973>.
22. About NCPWD. National Council for Persons with Disabilities, 2004. <http://ncpwd.go.ke/aboutncpwd/>.
23. Kenya Programmes for Disabled Persons (last updated September 14, 2012). <http://www.kabissa.org/directory/kpdp>.
24. About Northern Nomadic Disabled Persons' Organization (NONDO). <http://www.nondokenya.org/>.
25. WRC, Sexual and Reproductive Health and Disabilities Consultative Meeting, December 2-7 2012, Kakuma, Kenya (unpublished report).
26. Ibid.
27. National Coordinating Agency for Population and Development (NCAPD) and the Kenya National Bureau of Statistics (KNBS), "Kenya National Survey for Persons with Disabilities" (2008).
28. WRC, Sexual and Reproductive Health and Disabilities Consultative Meeting, December 2-7 2012, Kakuma, Kenya (unpublished report).
29. IRC registration records, December 2013.
30. WRC, Sexual and Reproductive Health and Disabilities Consultative Meeting, December 2-7 2012, Kakuma, Kenya (unpublished report).
31. Ibid.
32. Ibid.
33. HelpAge International and Handicap International. 2014. *Hidden victims of the Syrian crisis: disabled, injured and older refugees*. <https://data.unhcr.org/syrianrefugees/download.php?id=5812>. See also: WRC. 2014. *Disability inclusion: Translating policy into practice in humanitarian action*. <http://www.womensrefugeecommission.org/programs/disabilities/disability-inclusion>.
34. WRC, Sexual and Reproductive Health and Disabilities Consultative Meeting, December 2-7 2012, Kakuma, Kenya (unpublished report).
35. Some impairment descriptions were adapted from the Washington Group on Disability's classification. CDC. 2009. Washington Group on Disability: Statistics short set of questions on disability. [http://www.cdc.gov/nchs/washington\\_group/wg\\_questions.htm](http://www.cdc.gov/nchs/washington_group/wg_questions.htm).
36. MEASURE DHS, Demographic and Health Surveys, DHS Questionnaires. Last accessed July 18, 2013. Available from <http://www.measuredhs.com/What-We-Do/Survey-Types/DHS-Questionnaires.cfm>.
37. WHO, Adolescent Health. Last accessed July 18, 2013. Available from [http://www.who.int/topics/adolescent\\_health/en/](http://www.who.int/topics/adolescent_health/en/).
38. Maps where participants identified and labeled reproductive organs.
39. Walking through the journey of PWDs' lives, or a period of their lives, in order to identify events, behaviors and attitudes that are relevant to SRH.
40. Activities where participants sort and organize information into categories.
41. International HIV/AIDS Alliance. 2006. *Tools Together Now! 100 Participatory Tools to Mobilize Communities for HIV/AIDS*.
42. Martin Farmer and Fraser Macleod. 2011. *Involving Disabled People in Social Research*, Office for Disability Issues HM Government.
43. Morgan, David. 1996. *Focus Groups as Qualitative Research, Second Edition, Qualitative Research Methods Series 16*.
44. Handicap International Ethiopia. 2012. *HIV and AIDS and sexual and reproductive health knowledge, attitudes, practices and services utilization of persons with disabilities in Addis Ababa, Ethiopia*.
45. Maynard-Tucker G. "Conducting Focus Groups in Developing Countries: Skill Training for Local Bilingual Facilitators." *Qual Health Res* 2000, 10(3):396-410.
46. Adult female participants, Somali intellectual impairment group; December 9, 2013.

47. Adult female participants, English physical impairment group; December 4, 2013.
48. Adolescent boy participant, Somali hearing impairment group; December 8, 2013.
49. Adolescent boy participant, Somali intellectual impairment group; December 10, 2013.
50. Interview with Swahili-speaking caregiver of adolescent girl; December 7 2013.
51. Adult female participants, English physical impairment group; December 4, 2013.
52. Adolescent girl participant, Somali physical impairment group; December 5, 2013.
53. Adult male participant, Somali hearing impairment group; December 6, 2013.
54. Adult male participant, Somali hearing impairment group; December 6, 2013.
55. Caregiver, Somali focus group discussion; December 7, 2013.
56. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
57. Caregiver, Somali focus group discussion; December 7, 2013.
58. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
59. Adult female participants, Somali physical impairment group; December 3, 2013.
60. Adult female participant, Swahili physical impairment group; December 3, 2013.
61. Adolescent boy participant, Somali intellectual impairment group; December 10, 2013.
62. Adult male participant, Somali hearing impairment group, December 6, 2013.
63. Adult female participant, Arabic physical, vision, mild mental impairment group; December 5, 2013.
64. Adult female participants, Somali intellectual impairment group; December 9, 2013.
65. Adult female participants, Somali physical impairment group; December 3, 2013.
66. Adult female participant, Swahili physical impairment group; December 3, 2013.
67. Adult female participants, English physical impairment group; December 4, 2013.
68. Interview with Somali-speaking new mother with a disability; December 7, 2013.
69. Adult female participants, Somali physical impairment group; December 4, 2013.
70. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
71. Adult female participants, Somali intellectual impairment group; December 9, 2013.
72. Adolescent girl participant, Somali physical and intellectual impairment group; December 10, 2013.
73. Adolescent girl participant, Somali physical impairment group; December 5, 2013.
74. Adult male participant, Somali hearing impairment group; December 6, 2013.
75. Adolescent boy participant, Somali hearing impairment group; December 8, 2013.
76. Interview with Somali-speaking new mother with a disability; December 7, 2013.
77. Caregiver, Somali focus group discussion; December 7, 2013.
78. Adult male participants, Somali physical and mental impairment group; December 2 2013.
79. Adult male participants, Somali physical and mental impairment group; December 2 2013.
80. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
81. Adult female participant, Somali hearing impairment group; December 6, 2013.
82. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
83. Adult female participants, English physical impairment group; December 4, 2013.
84. Adult female participants, Somali intellectual impairment group; December 9, 2013.
85. Adult male participants, Somali physical and mental impairment group; December 2 2013.
86. Adolescent boy participants, Somali physical impairment group; December 5, 2013.
87. Adolescent girl participant, Somali physical impairment group; December 5, 2013.
88. Adolescent girl participant, Somali hearing impairment group; December 8, 2013.
89. Adult female participants, Somali intellectual impairment group; December 9, 2013.
90. Adult female participant, Arabic physical, vision, mild mental impairment group; December 5, 2013.
91. Adolescent girl participant, Somali physical and intellectual impairment group; December 10, 2013.
92. Adult female participants, English physical impairment group; December 4, 2013.
93. Adolescent boy participant, Somali intellectual impairment group; December 10, 2013.
94. Adolescent boy participant, Somali intellectual impairment group; December 10, 2013.
95. Adult female participants, Arabic physical, vision and mental impairment group; December 5, 2013.
96. Adolescent female participant, Somali physical, vision and mental impairment group; December 10, 2013.
97. Adolescent boy participant, Somali physical impairment group; December 5, 2013.
98. Adolescent girl participant, Somali physical and intellectual impairment group; December 10, 2013.
99. Adolescent girl participant, Somali hearing and speech impairment group; December 8, 2013.
100. Adolescent boy participant, Somali mild intellectual impairment group; December 10, 2013.
101. Interview with a Somali woman of reproductive age with a physical impairment; December 2, 2013.
102. Adolescent girl participant, Somali hearing and speech impairment group; December 8, 2013.
103. Interview with English-speaking 20-year old woman with multiple impairments; December 9, 2013.
104. Adult female participant, Somali hearing impairment group; December 6, 2013.
105. Adolescent girl participant, Somali hearing and speech impairment group; December 8, 2013.
106. Adult female participant, English physical impairment group; December 4, 2013.
107. Interview with English-speaking 20-year old woman with multiple impairments; December 9, 2013.
108. Adult female participant, Somali hearing impairment group; December 6, 2013.
109. Interview with English-speaking 19-year old adolescent girl with a physical impairment; December 7, 2013.
110. Interview with English-speaking 20-year old woman with multiple impairments; December 9, 2013.
111. Adult male participant, Somali hearing impairment group; December 6, 2013.
112. Adult female participant, Somali hearing impairment group; December 6, 2013.
113. Interview with a Somali woman of reproductive age with a physical impairment; December 2, 2013.
114. Adult female participant, Somali hearing impairment group; December

- 6, 2013.
115. Interview with English-speaking 19-year old adolescent girl with a physical impairment; December 7, 2013.
116. Interview with Swahili-speaking 45-year old woman with a physical impairment; December 9, 2013.
117. Interview with a Somali woman of reproductive age with a physical impairment; December 2, 2013.
118. Interview with English-speaking 20-year old woman with multiple impairments; December 9, 2013.
119. Adult female participant, Somali hearing impairment group; December 6, 2013.
120. Adolescent girl participant, Somali hearing and speech impairment group; December 8, 2013.
121. Adolescent boy participant, Somali hearing impairment group; December 8, 2013.
122. Adult female participant, English physical impairment group; December 4, 2013.
123. Interview with a Somali adolescent girl with a physical impairment; December 2, 2013.
124. Adolescent girl participants, Somali physical impairment group; December 5, 2013.
125. Adult female participant, Somali intellectual impairment group; December 9, 2013.
126. Caregiver, Somali focus group discussion; December 7, 2013.
127. Caregiver, Somali focus group discussion; December 7, 2013.
128. Adolescent girl participant, Somali physical impairment group; December 5, 2013.
129. Interview with English-speaking 20-year old woman with multiple impairments; December 9, 2013.
130. Interview with Swahili-speaking 19-year old girl with physical impairments; December 9, 2013.
131. Interview with English-speaking 45-year old woman with physical impairments; December 9, 2013.
132. Adolescent girl participant, Somali physical impairment group; December 5, 2013.
133. Caregiver, Somali focus group discussion; December 7, 2013.
134. Adult male participants, Somali physical impairment group; December 4, 2013.

## 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 only at <http://wrc.ms/Kenya-SRH-cards>)

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

## 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                                |
| <b>Denying access to services</b>  |
| Child labor  |
| <b>Emotional violence</b>  |
| Violence with words  |
| Making the person with a disability see traumatic acts                             |
| <b>Economic violence</b>   |
| Controlling money  |
| Not allowing opportunity   |
| Non-payment or low pay for work  |
| <b>Harmful traditional practices</b>   |
| Female genital cutting   |
| 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/Kenya-SRH-cards>.

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

| List of Photos                               |
|--|
| Ambulance                                    |
| Bush   |
| Don Bosco Vocational Training Centre         |
| Home   |
| Kakuma Secondary School                      |
| Latrine                                      |
| LWF compound                                 |
| Main hospital (IRC)                          |
| Main road/highway                            |
| Market                                       |
| Paediatric Occupational Therapy Centre       |
| Police post                                  |
| Reception area (refugee registration center) |
| Social Services Centre                       |
| Water collection point                       |

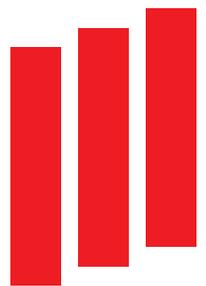
See the photos at [http://wrc.ms/SRH\\_disab\\_Kenya\\_photos](http://wrc.ms/SRH_disab_Kenya_photos).





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