Study on Sexual and Reproductive Health and Disabilities in Kampala’s Urban Displacement

Women’s Refugee Commission and Refugee Law Project
December 2013

REPORT FOR CONTRIBUTORS

WHO ARE WE?
The Women’s Refugee Commission (WRC) is a nongovernmental organization (NGO) based in the United States. We are a research and advocacy organization that works to protect the rights, safety and well-being of displaced communities around the world. We work with governments, United Nations (UN) agencies and international organizations.

The Refugee Law Project (RLP) is a community outreach project of the School of Law, Makerere University, Uganda. We work towards empowering forced migrants and host communities in Uganda to enjoy their human rights and lead dignified lives. This is done through research; provision of legal aid, mental health and psychosocial services, gender and sexual violence prevention services; and conflict, governance and transitional justice monitoring. Refugees with disabilities are among

Sexual and reproductive health

Everyone has a right to access the information and services that they need to take care of their sexual and reproductive health. This includes learning about how their bodies work as they become adults, as well as how to have safe relationships. This also includes access to safe, effective, affordable and acceptable methods of family planning (birth spacing), such as condoms and pills; access to health care that helps women have safe pregnancies and deliveries; access to services for survivors of sexual violence; and access to information and services on how to prevent and care for sexually transmitted diseases, including HIV.

Photo: Members of the study team.
RLP’s key target group, and RLP works with them to ensure that they enjoy their rights.

WHY DID WE COME TO KAMPALA?
We visited Kampala to undertake a study to find out more about the sexual and reproductive health needs and concerns of persons with different types of disabilities (physical, sensory, intellectual, mental and multiple impairments). We also wanted to learn more about what persons with disabilities thought should be done to improve the situation, including what they themselves could do.

WHAT DID WE DO IN KAMPALA?
Over two weeks in December 2013 and one week in January 2014, the WRC worked with RLP’s Mental Health and Psychosocial Wellbeing team to train 12 refugee researchers and participant recruiters to conduct the research among women with disabilities aged 20-49, men with disabilities aged 20-59 and adolescent girls and boys with disabilities aged 15-19, in Kampala. The refugee researchers and participant recruiters included persons with disabilities.

In total, the research team met with 104 refugees with disabilities—75 women and girls and 29 men and boys—with physical, visual, intellectual, mental, hearing and multiple impairments. They met with refugees who were homebound and 32 caregivers and family members of persons with disabilities. The activities were conducted in Swahili, Somali, Kinyarwanda and Luganda sign. Some activities were done in groups, while others were done with individuals.

By listening to participants, we learned about their thoughts and experiences. We are grateful to have met with them and for their permission to let us share the information and stories in a responsible way.

WHAT DID WE LEARN?
Early findings show that, overall, most persons with disabilities felt they are looked down upon because of their disabilities. All participants and caregivers felt there should be more considerations for persons with disabilities. The overwhelming request, especially from caregivers, was for them to be resettled, as many felt the care they could receive in Kampala was not enough for their dependent’s disability. Other suggestions included having fast-track options to receive services, instead of having to wait in a long queue with everyone else. Additional
requests included educational opportunities and vocational training for persons with disabilities and caregivers, so that they can communicate better with service providers and have the opportunity to work and earn an income.

In terms of health services, some persons with disabilities noted that they were treated well by health providers because of their disability. However, the majority of participants and caregivers complained about inadequate health services and maltreatment from health care staff. **Lack of translation**, including for sign language, and **lack of transport** to health facilities, as well as **lack of money to pay health providers**, were seen as barriers to accessing care. Many people seemed to agree that if they did not have money, as refugees and as persons with disabilities, they would be largely ignored and neglected by health providers. Some mentioned that they would wait all day to receive services, only to come home with nothing: “If you are disabled, you wait, wait, wait.”

**AWARENESS OF SEXUAL AND REPRODUCTIVE HEALTH**

Many people said InterAid, Mulago Hospital, RLP, African Centre for Torture Victims (ACTV) and Kampala City Council Authority (KCCA) provide information and services for sexual and reproductive health, although access to sexuality information was reported as difficult for persons with intellectual impairments in particular.

While some participants knew where the female and male reproductive organs were located on the body and how they worked, most were not very clear about their bodies. Those with intellectual impairments had more difficulty identifying and locating body parts, and were generally less aware about how they worked. Adolescent girls and boys also generally knew less than adults.

---

Photo: Example of a body map made by men with intellectual impairments. (Credit: RLP)

Most participants were aware of HIV or some symptoms of sexually transmitted infections, although they were not always familiar with their names or exact causes. They could also list several methods of birth spacing, including condoms, pills that a woman would take every day or injections that a woman would receive every three months. Others
mentioned the intrauterine devices (coil), a T-shaped device that is inserted into a woman’s womb, as well as female and male sterilization. While a handful of participants could name birth spacing methods, there was generally a lot of mistrust, as well as misconceptions, about family planning options. Many feared that condoms could get stuck inside a woman’s body, or could make a woman lose her fertility. Participants who were home-bound or had multiple impairments appeared to know less about sexual and reproductive health, especially as they had very limited opportunities to receive information from outside.

**Some birth spacing options**

<table>
<thead>
<tr>
<th>Condom</th>
<th>Pill</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Condom Image" /></td>
<td><img src="image2" alt="Pill Image" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Injection</th>
<th>Intrauterine device</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image3" alt="Injection Image" /></td>
<td><img src="image4" alt="Intrauterine Device Image" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Implant</th>
<th>For more information about birth spacing options, visit a health center.</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image5" alt="Implant Image" /></td>
<td><img src="image4" alt="Intrauterine Device Image" /></td>
</tr>
</tbody>
</table>

**GENERAL EXPERIENCE FOR A WOMAN OR GIRL WITH A DISABILITY WHO BECOMES PREGNANT**

Participants generally agreed that if a girl or woman with a disability becomes pregnant, whether or not she was married would affect how she would be treated by her family and neighbors. If she was married, the pregnancy would be welcome by the couple and her family. If she was not married, she would be discriminated. The family and neighbors would say she is “a prostitute,” that she “misbehaved” or that she “was raped.” For such an unmarried girl, participants said that she could keep the child, or her parents would force her to have an abortion.

When a pregnant girl or woman with a disability is ready to deliver her baby, participants said she would do so at the hospital or at home with a traditional birth attendant, her mother or by herself in secret. If she delivers at the hospital, she would go there by foot or by taxi. They also said a family member or the baby’s father may go with her.

Many participants felt that pregnant women and girls with disabilities would not be treated nicely and with respect by health providers, citing remarks such as: “How can you as a
refugee and disabled person be pregnant?” and “She is a problem and is giving birth to another problem.”

SAFETY CONCERNS
Participants with disabilities generally agreed that they feel most unsafe by the toilets and in their neighborhoods. Both of these places were cited as locations where risk of attack and rape were possible. Several participants were aware of post-rape care and the benefits of seeking health care after experiencing sexual violence.

Other places where participants felt unsafe were generally related to physical accessibility. For example, if a landmark had stairs or was very close to a road or water, participants felt it unsafe, especially for the physically or visually impaired.

Many participants, especially the home-bound, said they felt safe when they are with their family members and caregivers. Others—especially the mentally impaired—agreed they felt safe with an RLP counselor with whom they could talk about their concerns.

What are essential health services for survivors of sexual violence?
If a survivor of sexual violence seeks medical care immediately after the assault, she can:
- Receive care for physical wounds.
- Take pills to prevent unwanted pregnancy (within 5 days).
- Take medicine to prevent sexually transmitted infections.
- Take medicine to prevent HIV (within 3 days).
- Receive basic emotional support.
- Receive referrals to other services.

TREATMENT AND WHAT IS ACCEPTABLE
All participants agreed that violence against persons with disabilities is unacceptable. While forced sterilization was mostly seen as unacceptable, several participants reported that an unmarried disabled girl or woman may be forced to use a birth spacing method by her family to prevent a second pregnancy. Sterilization was also brought up for men or boys with disabilities, although if a disabled boy or man made a girl or woman pregnant, participants were more likely to think
that he was exercising his manhood: “The boy would be seen as a very strong man.”

WHAT WILL WE DO NOW?
The WRC and RLP will analyze the information further and write a full report on the findings with recommendations (including recommendations that participants shared) on how to improve sexual and reproductive health services for persons with disabilities in Kampala. We will share the report with donors, the UN High Commissioner for Refugees (UNHCR) and international and national NGOs.

A similar study is also being done in Kenya and Nepal. We will publish the findings from all three countries in one report and will advocate to governments, UN agencies and international and national organizations to push for improved sexual and reproductive health services for persons with disabilities around the world.

WHAT CAN YOU DO IF YOU WANT TO LEARN MORE ABOUT THIS STUDY AND THE REPORT?
For more information about this study, please contact: Yusrah Nagujja 414340547/0776897107. y.nagujja@refugeelawproject.org.

If you would like more information about the full report and the WRC’s advocacy about these findings, please contact Mihoko Tanabe at info@womenscommission.org or visit www.womensrefugeecommission.org.

This report was written by Mihoko Tanabe and reviewed by Yusrah Naguijja, Apio Molly and Sandra Krause. It was edited by Diana Quick. Images were drawn by Stacey Patino. Photos were taken by the RLP.

The research was conducted by: Afugu Miriam (sign interpreter); Apio Molly (transcriber); Banzi Josepha; Berlin Abdulkadir; Chirwa Francis; Gato Ndagaramiye Joshua; Fiona Iradukunda; Mami Agnes; Namiyingo Agnes (transcriber); Nimo Hassan Ali; Pascaline Kwinjda; and Viviane Mushimiyimana.