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Protection of Refugees with Disabilities

Uganda Fieldwork Report

August-September 2013





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The findings discussed in this report are drawn from research undertaken in 2013. For further information and research findings, please see other fieldwork reports and other publications, available on our webpage: http://blogs.usyd.edu.au/refugees-disabilities/.

Many thanks to UNHCR, the Ugandan Government, the Refugee Law Project, InterAid Uganda, NUDIPU, ARC and HIJRA and all the other organisations and individuals who facilitated our fieldwork and who continue to support refugees and persons with disabilities in Uganda. We reserve special thanks for Mr Mwesigwa Martin Babu, Ms Hannah Martin and Mr Riiza Vicent. Most importantly, we thank our refugee participants.

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2. Acronyms and abbreviations

AIRD African Initiatives for Relief and Development

ARC American Refugee Council

CRPD UN Convention on the Rights of Persons with Disabilities

DPO Disabled Persons Organisation
DRC Democratic Republic of Congo
EVI Extremely Vulnerable Person
ExCom UN Executive Committee

HRIT Heightened Risk Identification Tool

ICF International Classification of Functioning, Disability and Health

MTI Medical Teams International

NTISD Nsamizi Training Institute for Social Development

OPM Office of the Prime Minister

OURS Organized Useful Rehabilitation Service

PCU Pentecostal Church of Uganda

ProGres UNHCR's Profile Global Registration System

PSN Person with Special Needs REC Refugee Eligibility Committee

RLP Refugee Law Project

RSD Refugee Status Determination

SNC Specific Needs Code

UNAD Ugandan National Association of the Deaf
UNAPD Ugandan National Action on Physical Disability
UNHCR United Nations High Commissioner for Refugees

WASH Water, Sanitation and Hygiene

WFP World Food Program
WHO World Health Organisation
WRC Women's Refugee Commission

3. Executive summary

According to the United Nations High Commission for Refugees (UNHCR), the agency charged with caring for the world's refugees, in mid-2013 there were over 38 million displaced persons 'of concern' across the globe. This report shares findings from a project which seeks to shed light on the experiences of an often-overlooked subsection of this group: refugees who have disabilities. The project evaluates the protection and assistance given to persons with disabilities in displacement situations in six different host countries. To assist us in this task we have developed and tested a tool for identifying persons with disabilities within displaced populations. Adopting the functionality approach mandated by the UN Convention on the Rights of Persons with Disabilities (CRPD), our tool draws heavily from the *International Classification of Functioning, Disability and Health* (ICF). The project began in 2012 with fieldwork in Malaysia and Indonesia. In 2013, our team undertook research in Pakistan, before travelling to Uganda in late August for a total of three weeks. We travelled to Jordan and Turkey in 2014 to complete the project fieldwork.

This report presents the project's findings in relation to refugees with disabilities living in Uganda. It outlines the displacement experiences of both 'urban refugees' living in the Ugandan capital, Kampala, and those living in two government-run refugee settlements in the south of the country. It includes our findings on the types of disabilities affecting refugees and how and when these disabilities were acquired. We map existing mechanisms for protecting and assisting refugees with disabilities and review data on file with the United Nations High Commissioner for Refugees (UNHCR) and its partners in Uganda.

In this section we provide a brief overview of our findings and recommendations relating to the situation of refugees with disabilities in Uganda. As a state party to the UN *Convention Relating to the Status of Refugees* and its related *Protocol* (the Refugee Convention),⁵ the Ugandan government affords to refugees on its territory permanent residence – or an indefinite right to remain. Many refugees in Uganda live in government settlements, where they are allotted a piece of land and have access to basic services like food rations, provided by the World Food Program. They are also afforded primary health care, provided by UNHCR partners. Others live in urban centres, such as the capital, Kampala, where they find work to support themselves and their families. While some positive policies and programs are in place, refugees with disabilities in Uganda face many challenges.

3.1 Positive approaches

Our first impression of Uganda was that the country exhibits considerable generosity towards refugees. As a party to the Refugee Convention, Uganda has a long history of supporting refugees who have fled from neighbouring countries. At a personal level we experienced a warm welcome and generous support from various Ugandan government representatives, for which we express our gratitude.

We found that the disability rights movement in Ugandan civil society was relatively sophisticated. We noted the inclusion of Members of Parliament with disabilities, as well as persons with disabilities at every level of government. We observed a high level of interaction between the National Union of Disabled Persons of Uganda (NUDIPU) and the government, specifically the Ministry of Gender, Labour and Social Development. We also noted cooperation between Ugandan Disabled Persons Organisations (DPOs) and refugee advocates

¹ UNHCR, 'Mid-year Trends' (2013), 22

² For our previous discussions on refugees with disabilities see: Mary Crock, Christine Ernst & Ron McCallum, 'Where disability and displacement intersect: Asylum seekers and refugees with disabilities' (2012) 24(4) *International Journal of Refugee Law* 735; Mary Crock, Naomi Hart, Ron McCallum & Ben Saul, 'Making every life count: Ensuring equality for persons with disabilities in emergency situations' (2014) 40(1) *Monash University Law Review* 148.

³ See World Health Organization, 'World report on disability' (2011), 5.

⁴ Our publications can be accessed at: http://blogs.usyd.edu.au/refugees-disabilities/.

⁵ Convention Relating to the Status of Refugees, opened for signature 28 July 1951, 189 UNTS 137 (entered into force 22 April 1954) as amended by the Protocol Relating to the Status of Refugees, opened for signature 31 January 1967, 606 UNTS 267 (entered into force 4 October 1967). Uganda acceded to the Convention and its Protocol on 27 September 1976.

and service providers and strong interest amongst DPOs in increasing their involvement in activities which support refugees with disabilities. Ugandan DPOs have the potential to be a valuable resource for UNHCR and partners when designing or improving mainstream and specialised programs for refugees with disabilities. In its 2010 Executive Committee 'Conclusion on refugees with disabilities' UNHCR acknowledged the CRPD and recognised its application in displacement situations. Since then, UNHCR has sought to adapt its approach to disability through changes to existing programs and documents, as well as by publishing a Need to Know Guidance on working with refugees with disabilities. The agency is currently updating its registration procedures, providing the opportunity to bring these into line with the CRPD approach to disability. It was encouraging to see that the Need to Know Guidance had been adopted in condensed form in Uganda for staff sensitisation during early contact with refugee groups. UNHCR resettlement staff in Mbarara also showed familiarity with a recently-published Resettlement Assessment Tool for refugees with disabilities. They had been using this tool as a reference in building awareness amongst staff to encourage the identification and referral of refugees with disabilities to the resettlement unit.

Finally, we found that UNHCR and its partners had been actively engaged in promoting programs aimed at assisting and empowering refugees with disabilities. This has contributed towards improving the rights of these refugees. In the context of our research, Uganda stands out as the location where refugees with disabilities have been considered most actively. Short-term funding from Qatar-based One Billion Strong which was provided to UNHCR, Interaid Uganda and the Refugee Law Project (RLP) enabled these organisations to collect data and provide special assistance to refugees with disabilities. This funding also enabled the formation of associations of refugees with disabilities, who have been empowered through training and grants to implement income generating projects. Similarly, funding from ActionAid Uganda to the Uganda National Association of the Deaf (UNAD) has allowed this group to develop programs targeting HIV/AIDS reduction and improving education for the deaf community (including refugees) in Isingiro district.

3.2 Challenges for marginalized groups in development

Despite these positive developments, many challenges remain to ensuring the rights of refugees with disabilities. As a developing country, Uganda faces obstacles to adequately supporting persons with disabilities and addressing the many barriers to participation that they continue to face. This challenge is magnified for refugees, whom we found to be generally poorer and more socially isolated than their local counterparts. Those in the refugee settlements were also geographically remote from many important services, such as inclusive education and rehabilitation centres.

The physical layout of refugee settlements and even urban areas presents an obstacle to many refugees with disabilities, affecting their mobility. A lack of suitable transport and assistive devices exacerbates this. Such obstacles have an impact on many areas of life, including access to employment, education, health care, protection, food, water and social participation.

Stigma and discrimination, sometimes related to the manner in which disabilities were acquired and other times based on misunderstandings about the nature of certain conditions, can act as major barriers - sometimes even undermining the physical safety of those they affect.

Poverty and limited income generation options impact on the independence and agency of persons with disabilities, and further restrict their ability to address the other barriers they face. Limited access to sufficient and suitable food and water exacerbate existing conditions and can sometimes even cause disability.

Violence and abuse are issues for refugees with disabilities, and may also result in (further) disability acquisition. The challenges noted here – physical environment, stigma and poverty (and lack of agency) all contribute to creating situations in which the likelihood of being exposed to violence increases and the ability to seek redress is limited.

⁶ UN High Commissioner for Refugees (UNHCR), Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR, No. 110 (LXI) - 2010, 12 October 2010, No. 110 (LXI) - 2010, available at: http://www.refworld.org/docid/4cbeaf8c2.html.

⁷ UNHCR, Need to Know Guidance: Working with persons with disabilities in forced displacement (UNHCR, 2011).

⁸ Resettlement Assessment Tool: Refugees with Disabilities (UNHCR, 2013). Available at: http://www.unhcr.org/51de6e7a9.html.

For these reasons, the identification of refugees with disabilities is challenging, but also of fundamental importance in developing a better understanding of the needs and challenges faced by this group. Perhaps our most significant finding is that current identification practices are failing to capture all refugees with disabilities, or record their disabilities in a manner which respects the CRPD and other international standards.

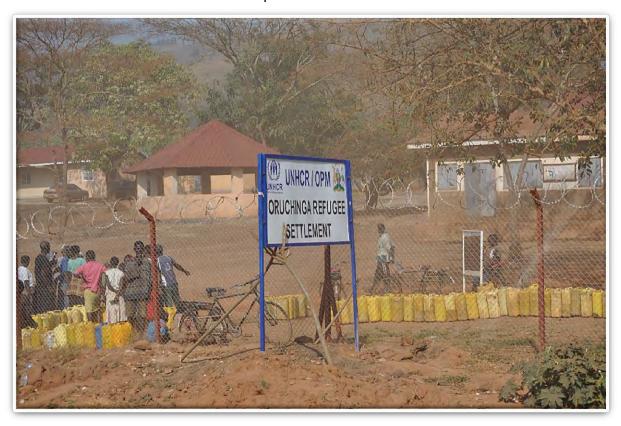


Image 1: Water collection at Base Camp, Oruchinga Refugee Settlement

3.3 Main recommendations: moving forward

- It is our view that UNHCR and its partners should continue to improve mechanisms for identifying refugees with disabilities, particularly emphasising the inclusion of systematic disability-related questions. Outreach exercises are essential to reaching more isolated individuals. While improvements have been made, UNHCR should reconsider the way it categorises refugees with disabilities to better align with the approach adopted by the CRPD.
- Long-term targeted or ear-marked funding would help ensure that resources reach refugees with
 disabilities and can be invested into their further empowerment. Identification and needs assessment
 could form a strong factual foundation on which to seek funding or interventions from specialist groups.
- Special attention needs to be given to improving the support and accommodation of refugees with mental illness or mental disabilities, especially those living without family. These persons are often overlooked in identification exercises and have limited access to services and procedures.
- We believe that UNHCR and its partners should continue to engage with local organisations, including Ugandan DPOs, in the design and implementation of programs to assist and empower refugees with disabilities. Associations of refugees with disabilities should also be included in these activities, with a stronger consultative status.
- Ugandan DPOs should consider the inclusion of associations of refugees with disabilities in their activities and umbrella bodies. DPOs could provide a valuable model, and source of information and mentorship for these associations, as well as becoming powerful advocates for the rights of refugees with disabilities.

- UNHCR and its partners should continue to develop and deliver programs to train their own staff, and
 provide training to other organisations (eg Ugandan police and medical personnel), in how to work with
 refugees with disabilities. UNHCR's Need to Know Guidance can provide the foundation for such
 programs.
- Donors should support programs that seek to *empower* refugees with disabilities, rather than provide charity or encourage dependence. They should create standards that demand disability inclusiveness.
 For example, all funding proposals should be required to address the issue of how programs will ensure the inclusion of persons with disabilities. Specialised programs should recognise and invest in the endless potential of refugees with disabilities, for example through a focus on livelihoods and leadership skills.

4. Terms and approaches

In this section we outline what we mean when we speak about refugees and about disability.

4.1 Rights-based approach to disability

Our approach to disability aligns with the approach adopted in the UN Convention on the Rights of Persons with Disabilities (CRPD),⁹ which, in article 1, states that:

Persons with disabilities include 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.

As such, our research does not limit its focus to impairments. Rather, our aim is to better understand how persons with disabilities are affected in displacement situations in terms of the barriers that exist to participation, protection and assistance. Uganda is a party to the CRPD.¹⁰ As an agency of the UN, UNHCR is bound by the CRPD and has officially undertaken to uphold the rights and responsibilities enshrined therein.¹¹

The *International Classification of Functioning, Disability and Health* (ICF), developed and promoted by the World Health Organisation (WHO), focuses on person's ability to function (functionality). It places the emphasis on whether or not persons with disabilities are able to participate in daily activities, rather than limiting disability to only certain causes or impairments. This means that chronic illness or injury may also be considered a disability.¹²

The existence of barriers to participation is of high importance in this approach, reflecting the CRPD approach to disability. ¹³ Put in concrete terms, a person with poor eyesight may not be considered 'disabled' if their impairment is corrected with glasses. Denied an assistive device, such a person becomes a person with a disability. Regardless of assistive devices, the experience of disability is still greatly dependent on context. If information sources are in accessible formats and built environments accommodate the needs of people with low vision, for example, these people are likely to face fewer barriers.

In what follows, we will identify barriers – be they related to procedure, built environments, social attitudes or legal status - and evaluate the approaches being taken to overcome them.

4.2 Refugees

While some of the services and some of the issues described in this report are available to or relevant to a larger group, we have limited the focus of our research to refugees. Pursuant to the Refugee Convention, a refugee is defined as anyone who:

Owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his [or her] nationality [or usual residence] and is unable or, owing to such fear, is unwilling to avail himself [or herself] of the protection of that country.¹⁴

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⁹ Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

¹⁰ Uganda ratified its membership to the CRPD and its Optional Protocol on 25 September 2008.

¹¹ See its Executive Committee's Conclusion: Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR, ExCom Conclusion No. 110 (LXI), 12 October 2010. Available at: http://www.unhcr.org/4cbeb1a99.html.

¹² UNHCR, Need to Know Guidance: Working with persons with disabilities in forced displacement (UNHCR, 2011), 3.

¹³ See World Health Organisation, World report on disability (2011, World Health Organisation and World Bank), 4.

¹⁴ See article 1 (a)(2), *Refugee Convention*.

Unless otherwise specified, this means that when we refer to refugees we include both those who have been granted refugee status by the Ugandan government, and persons seeking refugee status who, *prima facie*, fit the above definition. When referring to displacement or displaced persons, we mean people displaced outside their country of nationality (ie refugees), rather than internally displaced persons, unless the latter are explicitly mentioned.

5. Methodology

5.1 The fieldwork

Three weeks of fieldwork were undertaken in Uganda in 2013. Professors Mary Crock and Ron McCallum and Laura Smith-Khan and Hannah Martin spent the first week in the capital, Kampala, where they participated in a number of meetings with senior government officials, NGOs and events run by Ugandan Disabled Persons Organisations (DPOs). The majority of these activities were coordinated by Mr Mwesigwa Martin Babu (National Union of Disabled Persons of Uganda (NUDIPU)), who is a member of the UN Committee on the Rights of Persons with Disabilities, together with Professor McCallum. Mr Babu also assisted in gaining research clearance for our project from the Uganda National Council for Science and Technology and obtaining official permits from the Refugee Commissioner for our team to enter and conduct research in the refugee settlements.

In Kampala Professor McCallum presented a lecture on the worldwide implementation of the CRPD, which was hosted by NUDIPU and the Ministry of Gender, Labour and Social Development. The Hon. Kahinda Otafiire, the Ugandan Minister of Justice and Constitutional Affairs, presented a response. This lecture was attended by a number of current and past members of the Government of Uganda, as well as prominent members of civil society.

During our first week in Kampala, we met and interviewed UNHCR staff, including the Country Representative and Senior Community Services Officer. We also visited the Refugee Law Project (RLP) (based in Makarere University) and interviewed the RLP Director and the coordinator of their disability program.



Image 2: The researchers meet UNHCR Country Representative, Mr Mohammed Abdi Adar, and Senior Community Services officer, Ms Elsa Bokhre, in Kampala

During the second and third weeks, Professor Crock and Ms Smith-Khan were joined by Professor Ben Saul. We travelled to south-western Uganda and spent nine days there, conducting research in Mbarara city and Nakivale and Oruchinga Refugee Settlements (Isingiro District). This included interviews with UNHCR in Mbarara, as well as visits to a local school, an Inspector of Schools, a children's rehabilitation service and the office of a local DPO.

In Nakivale Refugee Settlement, we met with UNHCR's implementing partners, American Refugee Council (ARC) and Medical Teams International (MTI), a Settlement Commandant, and the Chairperson of the Nakivale Association of Refugees with Disabilities. The latter, along with ARC, helped coordinate a meeting and interviews with refugees with disabilities. We began by administering our questionnaire with refugees who

were known to have disabilities. However, as word spread of our presence in the settlement, we were overwhelmed by the numbers of people who came forward, wanting to participate. This led us to make extra copies of our questionnaire and distribute them amongst the community to be completed with the assistance of community leaders and left with ARC for us to collect.

ARC also assisted us in travelling to different parts of the settlement. In one area we conducted two gender-segregated discussion groups with refugees with disabilities. In another, we visited a village in which a street of housing had been provided for PSNs, including persons with disabilities.

In Oruchinga Refugee Settlement, we met with staff from HIJRA, UNHCR's community services partner there. We also spoke with the Settlement Commandant. We conducted another two discussion groups, visited a World Food Program (WFP) distribution centre, and visited the homes of some refugees with disabilities living outside the Base Camp area. We briefed our interpreting team on the questionnaire and provided them with copies to be administered with people interested in participating.

Upon our return to Kampala, we conducted debriefings with UNHCR Kampala and the RLP. We interviewed staff at Interaid Uganda, an urban implementing partner. We also conducted a further two discussion groups with urban refugees with disabilities: one at RLP and a short discussion at Interaid Uganda. Finally, we met the Refugee Commissioner, Mr Kazungu David Apollo, and debriefed him on our fieldwork.

5.2 Interviews and discussion groups

Handwritten notes were used to record data in the interviews and discussion groups. Questions were generally open-ended, and emerged as the research progressed and areas requiring clarification or elaboration were identified. Group discussions in the refugee settlements were gender-segregated to facilitate equal participation and also in response to the large numbers. Still, group numbers were higher than desirable (around 30 to 40 participants each): discussions were held in public areas and attracted so much interest; it was challenging to restrict participation. To help address the shortcomings of engaging with such large numbers, we gave participants the opportunity to speak with us one-on-one for a short time after the discussion, in order to share any sensitive information that they did not feel comfortable discussing in front of the group.

Where possible, the interviews were also audio-recorded. Upon returning to Sydney, the audio and handwritten data were transcribed in Microsoft Word and imported into NVivo 10 research software for coding and analysis.



 ${\it Image 3: The researchers walk\ towards\ a\ group\ discussion\ during\ outreach\ in\ Nakivale\ Refugee\ Settlement.}$

5.3 Questionnaires

A copy of the questionnaire used in Uganda is appended to this report. The questionnaire begins with a demographics section which covers basic information about participants. Name and UNHCR identifiers are included. These were useful in identifying and excluding duplicate responses. For the 49 questionnaires we personally administered with refugees, we were assisted by refugee interpreters working in both English and French. In Nakivale, we were overwhelmed by the interest shown in our research. This led us to decide to distribute copies of the questionnaire for self-completion. We distributed 300 copies amongst community leaders, who assisted the participants. We accepted completed questionnaires in both English and French. The interest in the project was such that when we returned a few days later to collect the completed questionnaires from the ARC centre, we discovered that hundreds of extra copies had been made. Having had this experience in Nakivale, we adjusted our approach in Oruchinga. Rather than attempt to administer the interviews, we briefed the refugee interpreters/community leaders there and provided them with questionnaires so that they could go out into the community and interview participants. The ARC provided a summary of a further 195 questionnaires that were left with them after our departure from Nakivale.

In total, we collected nearly a thousand questionnaires (including those we had administered). Once we had identified and consolidated 13 duplicate pairs of questionnaires, we were left with 970 completed questionnaires to analyse. Upon returning to Australia, these were transcribed into electronic versions of the forms in Microsoft Word. Responses, which were entered into form fields, were then extracted and saved in plain text format ('.txt'), before being imported into a Microsoft Excel spreadsheet for analysis and into NVivo 10 for further analysis and triangulation with other data.

5.4 Questionnaire participants

As mentioned above, we collected 970 questionnaires from participants in Nakivale and Oruchinga. We expressed an interest in speaking with people who were considered (or considered themselves) to have a disability, however we did not strictly control this, especially once we decided to accept self-completed questionnaires. Below is a breakdown of participants, outlining their gender, country of origin and their place of residence in Uganda. This included four participants who claimed to live in Kampala, but were presumably in Nakivale to participate in the verification exercise that was being completed at the time of our research – most probably they were officially listed as residing in a settlement.

Table 1: Questionnaire	participants	: bv aende	r. countrv o	f oriain and	current place o	f residence.

	Place of residence												
		Na	kivale		Or	Oruchinga Kampala				Overall			
Country of													
origin	F	М	Unspec.	Total	F	М	Total	F	М	Total	Total F	Total M	Total
Burundi	122	149	2	272	37	5	42				159	153	314
DRC	191	184	4	379	29	9	38				220	193	417
Rwanda	34	42		76	10	3	13				44	45	89
Somalia	63	51	1	115				1	3	4	64	54	119
Sth Sudan	2	2		4							2	2	4
Unspec'd	3	5	1	9	12	5	17				15	10	26
Total	415	433	8	856	88	22	110	1	3	4	504	458	970

Allowing self-completion uncovered many challenges and areas for improvement in the questionnaire's design. Given that many refugees were literate in French, providing a translated version would have facilitated comprehension and made participants less reliant on community members who were literate in English. In

some cases, participants did not complete responses for all questions, as indicated by 'unspecified' responses in the above (and following) tables and graphs.

The inclusion of a typing error inadvertently led to an interesting observation. Question 15.3 asks 'Are there any obstacles that prevent you accessing food?'. Question 15.6 was supposed to read 'Are there any obstacles that prevent you accessing water?'. Instead it read the same as Question 15.3, effectively asking participants the same question twice. Interestingly, in many cases, participants provided extra information at 15.6, indicating the value of including multiple questions around an important research theme. This information was incorporated into 15.3 for analysis, with any relevant information on water access added into 15.6.

Question 17, 'Have you required access to medical or rehabilitation services?' appeared to be frequently misunderstood, as many people responded 'No', but then went on to answer a subordinate question, indicating that they had had some access but needed more, or had not been able to access any services that they needed. Where it was clear from surrounding responses that the participant had indeed needed access to medical or rehabilitation services, their response was changed to 'Yes' during transcription.

We are also aware of the potential influence that our status as foreign researchers may have had on obtaining accurate data on access to assistance and services. While we constantly emphasised the fact we were academics, were only conducting research and were unable to provide material or procedural assistance, the number of participants and their enthusiasm suggested that they still hoped for assistance out of their participation. There is a possibility that this may have led to exaggerated responses in terms of the lack of access to assistance.¹⁵



Image 4: The team explains the research to participants in Nakivale Camp Photograph by Ben Saul/University of Sydney

¹⁵ Zoltan Dörnyei, Research Methods in Applied Linguistics: Quantitative, Qualitative, and Mixed Methodologies (2007, Oxford University Press) 54; C.S. Hutz and S.H. Koller, 'Methodological and Ethical Issues in Research with Street Children' (1999) (85) New Directions for Child and Adolescent Development 59, 66.

6. UNHCR and its partners: pre-existing initiatives



Image 5: Signs guiding the way to various services in Nakivale Refugee Settlement

6.1 UNHCR and its partners in Uganda

In Uganda, UNHCR works in cooperation with a number of partners. These partners vary in each location. Uganda is a party to the Refugee Convention and its Protocol¹⁶ and its government is responsible for refugee registration and status determination (RSD), with technical assistance from UNHCR. In each Refugee Settlement, including Nakivale and Oruchinga, 'commandants' from the **Office of the Prime Minister (OPM)** oversee land allocation and address security issues, referring serious reports to the police. They are also responsible for issuing permits for refugees to leave the settlement for extended periods – for example, when they wish to seek employment, or for short trips to receive medical or rehabilitative services.

In Nakivale, **American Refugee Council (ARC)** is UNHCR's implementing partner, responsible for protection, community services, water and sanitation, as well as providing running a reception centre. In Oruchinga, these functions are carried out by another implementing partner – **HIJRA**. In both locations, **Windle Trust Uganda** is responsible for education and **Medical Teams International (MTI)** is responsible for health and nutrition.¹⁷

¹⁶ Uganda is also a party to the Organization of African Unity's Convention Governing the Specific Aspects of Refugee Problems in Africa, 10 September 1969, 1001 UNTS 45, to which it acceded on 7 August 1987.

¹⁷ UNHCR's implementing partners change periodically. For example, ARC has only recently taken up its role. Many of the research participants mention interactions with the previous partner, GTZ.

The **World Food Program (WFP)**, through **Samaritan's Purse**, provides food rations to those who have UNHCR ration cards. The **African Initiatives for Relief & Development (AIRD)** provide logistical support for food and drug distribution, transportation of medical, protection and resettlement referrals, construction of shelters and other buildings, and other civil works for UNHCR.¹⁸

In Nakivale the ARC and the (government-run) **Nsamizi Training Institute for Social Development (NTISD)** are responsible for livelihoods and environment, while in Oruchinga these fall within the responsibilities of the **Pentecostal Church of Uganda (PCU)** and **Fida International**.

UNHCR's partners in Kampala include **Interaid Uganda**, and the **Refugee Law Project (RLP)**. Both have been involved in activities and programs assisting and empowering refugees with disabilities, including both urban refugees and those living in settlements. The RLP also plays a crucial role in conducting and disseminating research on refugees with disabilities and other thematic studies, including recent work on refugee women and girls¹⁹, and sexual violence against men and boys.²⁰

Networking and partnerships with other organisations is also important. For example, Interaid Uganda works with NUDIPU and a number of institutions, hospitals and other organisations to source suitable assistance and opportunities for urban refugees, including those with disabilities. UNHCR and its partners in Nakivale and Oruchinga coordinate with regional hospitals, rehabilitation services, and mainstream and speciality schools.

6.2 UNHCR initiatives

Internationally, UNHCR has taken a number of steps which demonstrate its commitment to the CRPD. Below, we will outline a number of relevant initiatives which either directly relate or are relevant to accommodating disability. We will also briefly explain how these initiatives have been incorporated in Uganda. These initiatives will be relevant to the findings presented in later

6.2.1 UN Executive Committee Conclusion

In its 2010 Conclusion²¹, the Executive Committee of UNHCR acknowledged the CRPD and made a number of recommendations to promote the protection and assistance to refugees with disabilities. It recognises the barriers that may be faced by displaced persons with disabilities and lists a number of steps to be taken by UNHCR and States parties to overcome these. These include addressing discrimination and raising awareness; 'swift and systematic' identification and registration of refugees with disabilities, including needs assessment; inclusion in and access to both mainstream and specialised services (and involvement in their design and implementation); and making all communication accessible.

More specifically, the Conclusion underlines the need to enable access to education, assistance and protection for young persons with disabilities, as well as allowing women and girls with disabilities access to protection programs. The Conclusion encourages States and UNHCR to improve the living conditions for refugees with disabilities by ensuring access to relevant programs. Finally, the document calls on States and UNHCR to provide refugees with disabilities equal access to Refugee Status Determination procedures and to durable solutions. It requests UNHCR to ensure that its policies, guidelines and operating standards are consistent with the terms of the Conclusion.

¹⁸ AIRD, 'Uganda', http://airdinternational.org/where-we-work/uganda/; UNHCR Uganda, Sub-Office Mbarara, 'Fact Sheet 2013'.

¹⁹ From the Frying Pan into the Fire: Psychosocial challenges faced by vulnerable refugee women and girls in Kampala (Refugee Law Project, April 2014).

²⁰ See for example, Chris Dolan, 'Has Patriarchy been Stealing the Feminists' Clothes? Conflict-related Sexual Violence and UN Security Council Resolutions', (2014) 45(1) *IDS Bulletin* 80.

²¹ UNHCR Executive Committee, 'Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR', Conclusion No 110 (LXI), 12 Oct 2010, available at: http://www.unhcr.org/4cbeb1a99.html accessed 30 January 2013

6.2.2 Need to Know Guidance

In 2011, UNHCR published *Working with Persons with Disabilities in Forced Displacement* ('Need to Know Guidance').²² This aligns with the CRPD and the ExCom Conclusion, emphasising equal access to basic human rights and recognising the role environmental and social barriers can play in creating disability. Further, it lists action to be taken to ensure access to each of these rights. In explaining its objective, the guidance states that:

[I]t is important for UNHCR to ensure that the rights of persons with disabilities who are of concern to the Office are met without discrimination. This places an onus on offices to develop a thorough understanding of the circumstances of persons with disabilities under their care.²³

The Need to Know Guidance specifies a number of goals that need to be met, including:

- making programming rights-based;
- ensuring identification and registration of persons with disabilities;
- establishing effective referral systems;
- raising awareness about disability rights and combatting discrimination;
- ensuring the physical security of persons with disabilities;
- making education inclusive;
- making information accessible;
- making food and non-food distribution accessible;
- · ensuring reunification and durable solutions are inclusive;
- · making buildings such as UNHCR offices and housing accessible; and
- ensuring that accessible transportation is available to persons with disabilities.

The *Need to Know Guidance* articulates measures that need to be taken in order to achieve these goals, emphasising that UNHCR is responsible for taking steps to ensure the rights of persons with disabilities. It acknowledges that discrimination is not always active or conscious: it can include a failure to take action to remove barriers that exclude certain persons.²⁴

Uganda was the first country in which we observed that UNHCR had explicitly incorporated this *Need to Know Guidance* into sensitisation materials for their staff. UNHCR staff in the Mbarara office shared a copy of a condensed (single A4 sheet) version. They mentioned using it as a checklist especially at the early stages, when meeting influxes in border areas and when new groups first arrive in the settlements. Both InterAid and the RLP also report using this tool as the basis of staff training and awareness building initiatives. This is an important step towards staff sensitisation and improving disability inclusion.

6.2.3 Age, Gender and Diversity Approach

When discussing the protection and assistance of persons with disabilities, UNHCR makes reference to its Age, Gender and Diversity Policy.²⁵ This policy recognises that '[t]he differences between peoples, whether actual or perceived, can be defining characteristics that play a central role in determining an individual's opportunities, capacities, needs and vulnerability.' It acknowledges that persons with diverse characteristics are likely to face diverse barriers to their equal participation and access to rights and makes a commitment to providing protection and assistance in such a way as to recognise this diversity and minimise these barriers. The policy mentions potential barriers faced by persons with disabilities and how these may be exacerbated during displacement. It requires the participation of persons with disabilities in 'identifying and developing appropriate solutions to disability challenges during and because of forced displacement.'²⁶

²² UNHCR, Working with Persons with Disabilities in Forced Displacement: Need to Know Guidance (2011).

²³ UNHCR, Working with Persons with Disabilities in Forced Displacement: Need to Know Guidance (2011) 2.

²⁴ UNHCR, Working with Persons with Disabilities in Forced Displacement: Need to Know Guidance (2011) 4.

²⁵ UNHCR, Age, Gender and Diversity Policy, 8 June 2011, available at: http://www.unhcr.org/refworld/docid/4def34f6887.html.

²⁶ UN High Commissioner for Refugees, *Age, Gender and Diversity Policy*, 8 June 2011, available at: http://www.unhcr.org/refworld/docid/4def34f6887.html [accessed 8 February 2013], 5.

This policy is used to inform participatory assessments amongst displaced populations. At the time of our research, ARC was preparing to lead an Age, Gender, Diversity Mainstreaming Participatory Assessment and provided us with a copy of the 'Truncated Guidelines, Themes and Suggested Questions' being used for this exercise. It was interesting to note the absence of any explicit reference to disability in these guidelines. Staff representatives did, however, mention that they actively involved persons with disabilities in the exercise.

6.2.4 ProGres

A central, electronic database that allows uniform data recording across populations of concern, the ProGres system has been rolled out in at least 72 countries worldwide.²⁷

Within this system, the way UNHCR categorises disability – when it is recorded – is narrower and focuses on impairment rather than barriers. Disability codes include: physical disability – moderate and severe, mental disability – moderate and severe, visual impairment, hearing impairment and speech impairment. A staff member involved in entering data in the verification exercise in Nakivale said she believed she was only supposed to select one disability code per person, but had been recording multiple codes when this was necessary, as she understood that refugees often had multiple impairments and that if these were not all recorded, comprehensive follow-up would be hindered.

The table below²⁸ indicates the sub-categories included under UNHCR's 'Disability' category, along with their corresponding codes. It should be noted that mental illness is not included within the disability category, but rather within the 'Serious medical condition' category (hence the different coding). It is interesting to compare this table with a previous version provided in the WRC report, which suggests that UNHCR have taken on board some of the recommendations made there. For example, the WRC noted that the definitions for 'Mental disability' included the words 'mental illness', demonstrating confusion as to the delineation between the two, potentially leading to inconsistent coding. While it is an improvement to note that the definitions for 'Mental disability' no longer refer to mental illness, the difference between who would be categorised as the former and who the latter is still not clear.

Another issue is that focusing on the impairment may misconstrue the severity level of disability. For example, in the 'Physical disability – moderate', the definition includes the example of 'persons who lost fingers or limbs, which may be corrected with a prosthetic device.' What this fails to recognise is the relevance of available assistance and accommodation: the lived experience of someone who has a suitable prosthetic device, accommodating employment options and an accessible built environment is likely to have a very different experience to someone who lacks these.

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²⁷ Microsoft 'ProGres Refugee Registration Platform'. Available at: http://www.microsoft.com/about/corporatecitizenship/en-us/partnerships/united-nations-agencies.aspx (accessed 14 October 2013).

Table created using 'Guidance on the Use of Standardized Specific Needs Codes' (UNHCR, DIPS/DOS 10 June 2009). Available at: http://data.unhcr.org/imtoolkit/chapters/view/registration-in-emergencies/lang:eng.

Table 2: UNHCR Categories and codes relating to disability

Subcategory	Description	Code
Visual impairment	Person who has a visual limitation from birth or resulting from illness,	DS-BD
(including blindness)	infection, injury or old age, which impacts daily life, may restrict independent movement, or require on-going treatment, special education or regular monitoring.	50 55
Hearing impairment	Person who has a hearing limitation from birth or resulting from	DS-DF
(including deafness)	illness, infection, injury or old age, which impacts daily life, and may require regular treatment, special education, monitoring or maintenance of artificial hearing device. The person may be able to communicate through sign language.	
Physical disability –	Person who has a physical impairment from birth or resulting from	DS-PM
moderate	illness, injury, trauma or old age, which does not significantly limit the ability to function independently. This category may include mine victims and persons who lost fingers or limbs, which may be corrected with a prosthetic device.	
Physical disability –	Person who has a physical impairment from birth or resulting from	DS-PS
severe	illness, injury, trauma or old age, which severely restricts movement, significantly limits the ability to function independently or pursue an occupation, and/or requires assistance from a caregiver.	
Mental disability -	Person who has a mental or intellectual impairment from birth or	DS-MM
moderate	resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently and interact, but may require special education, some monitoring and modest medication.	
Mental disability -	Person who has a mental or intellectual impairment from birth or	DS-MS
severe	resulting from illness, injury, trauma or old age, which significantly limits the ability to function independently or to pursue an occupation. It requires assistance from a caregiver, and may require medication and/or medical treatment.	
Speech impairment /	Person who is unable to speak clearly from birth or resulting from	DS-SD
disability	illness, injury, trauma or old age, which restricts or limits the ability to function independently, and may require speech therapy or medical intervention. The person may be able to communicate through sign language.	
Mental Illness	NB: Falls within the 'Serious medical condition' category (rather than the Disability category) and captures persons with a 'mental or psychological condition which impacts on daily functioning'.	SM-MI

6.2.5 Heightened Risk Identification Tool

UNHCR's Heightened Risk Identification Tool (HRIT) (currently version 2) is a multi-purpose tool, which is designed to be used by UNHCR staff in a variety of areas, including community services and protection.²⁹ It can be used in survey form, targeting a sample of a community; or with particular individuals who are considered likely to be at risk in order to determine whether they are at 'heightened risk', in order to prioritise the provision of assistance and protection.³⁰ The HRIT's accompanying guide offers two alternative methodologies for implementing the tool. The first is a structured, one-on-one interview with an individual at

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²⁹ UNHCR, HRIT Version 2 User Guide (July 2010), 2.

³⁰ UNHCR, HRIT Version 2 User Guide (July 2010), 3.

risk, or the representative of a family group. The second is a checklist approach, which considers the same indicators, but relies on the interviewer's prior knowledge of the individual or family and their context.³¹

The tool commences with a bio-data section, and interview details. It then proceeds to explore a number of risk areas. These include:

- Older people
- Children and adolescents
- Women and girls at risk
- · Legal and physical protection
- Health and disability

For each area, there are between one and five specific questions. Interviewers are instructed to conduct the interviews in 'a relaxed manner, similar to a discussion rather than a formal interview.' ³² The 'Health and disability' section includes two questions:

Do you / your family have any health problems, conditions or disabilities?

What treatment or care do you / your family member(s) receive for these health problems? What support do you need to address these problems?

This is followed by 13 risk indicator categories, including equivalents each of UNHCR's disability subcategories (set out in Table 2 in the previous section), as well as some relating to serious medical conditions. Alongside each indicator are suggestions for how it may be coded in ProGres.

Once again, the two indicators which relate to mental health and trauma present the greatest challenges. They read as follows:

- 3. 'Mental illness' (Person who has a mental illness of any cause, including depression, anxiety, disorder, psychosis, epilepsy and somatisation disorder). Code suggestions: SM-MI (Serious medical condition, mental illness), DS-MS (Mental disability severe), DS-MM (Mental disability moderate).
- 6. Bodily injury and / or psychological trauma caused by torture and / or violence, including sexual and gender-based violence). Code suggestions: TR-PI (Psych. and/physical injury due to torture), DS-MS, DS-MM.

Here, mental illness and mental disability are once again conflated, creating confusion as to which would be the appropriate codes to use. However the HRIT Guide does caution that it is 'only a rudimentary tool' and that 'the SNC should preferably only be entered into proGres after a full, follow-up assessment has been made'.³³

The Guide explains that interviewers will identify risk indicators through observation or from the responses given. It specifically directs interviewers to rely on the open questions provided and not to use the risk indicators as questions.³⁴ While this avoids direct questioning on traumatic issues, there is a risk that unless more guidance is given to interviewers in terms of the kinds of probing follow-up questions they can or should ask to elicit information covering all risk indicators, some disabilities may be overlooked.

By addressing different areas which may lead to higher risk, the HRIT acknowledges that multiple variables may impact on a person's security and wellbeing. The HRIT also emphasises creating interview settings where participants feel safe and in control, giving particular guidance for interviews with children.

³¹ UNHCR, HRIT Version 2 User Guide (July 2010), 11.

³² UNHCR, HRIT Version 2 User Guide (July 2010), 6.

³³ UNHCR, HRIT Version 2 User Guide (July 2010), 9.

³⁴ UNHCR, HRIT Version 2 User Guide (July 2010), 9.

Still, relying on disability risk indicators that mainly focus on impairments limits our understanding of how social, physical and legal barriers may create disability. While this updated version has greatly expanded its inclusion of disability-related risk indicators, some of the WRC's criticisms of the original still ring true. In its 2008 report, the WRC highlighted the danger in limiting disability to special needs or heightened risk in profiling settings, arguing that:

This can result in ignoring the skills and potential of persons with disabilities. Moreover, the tendency, especially in the HRIT, to see disability as a special health need means that there may be an overemphasis on medical responses, while ignoring disabled persons' other rights and needs and the social, physical and environmental barriers they face to participating fully in society.³⁵

These are challenges which still remain and need to be addressed in order to work towards a more inclusive system that reflects the CRPD approach to disability.

In Uganda, InterAid reported using the HRIT to conduct vulnerability assessments for refugees presenting to them, including those that may have disabilities. UNHCR staff in Mbarara indicated that the HRIT in its complete form was impractical for their context, noting that it was too time-consuming to effectively be used as a preliminary identification tool. Further, when it *is* used, a follow-up more detailed assessment is required anyway, involving further investment of time and resources. They noted that they had modified it in a data profiling exercise on women at risk, shortening it to make it more practical to implement.

We observed a kind of adaptation being used in their verification exercise in Nakivale refugee settlement. There, in the section (or 'desk') dedicated to persons with special needs (PSNs), staff interviewed individuals who had been flagged as at risk. They conducted short interviews to determine risks, completing a double-sided A4 form which included check boxes for children at risk, older persons, women and persons with disabilities, without explicitly setting out all the possible risk indicators. There is no mention of legal or physical protection risks, probably since these are dealt with by a separate verification desk.

The officer is asked to set out the assistance the interviewee requests and the assistance that the officer believes the interviewee requires. Rather than having high, medium and low responses for each risk area, this form has a final pair of check boxes where officers are asked to determine whether the persons is an Extremely Vulnerable Individual (EVI) or a Person with Special Needs (PSN). Each officer completes around 40 interviews per day during the verification. Like the HRIT, these initial interviews are supposed to be followed by more detailed home-visit assessment, but this is logistically challenging.³⁶ Being placed on the lists of PSNs or EVIs is regarded as important in terms of access to support. This includes access to higher ration quantities.

6.2.6 Resettlement Assessment Tool

A recent development has been the creation of guidelines for disability inclusion in resettlement: the *Resettlement Assessment Tool: Refugees with Disabilities*,³⁷ which was published in 2013. This is a sensitisation tool designed specifically for UNHCR staff working in resettlement. In particular, it emphasises that persons with disabilities may be submitted under any resettlement category – not only the medical category. This marks a considerable shift from past resettlement guidance relating to refugees with disabilities. It urges early identification and needs assessment and states that resettlement procedures must be made accessible to persons with disabilities. In assessing suitability for resettlement, officers are advised to consider the barriers the person would face if they were to remain in the host country or be repatriated. While refugees in Uganda are only considered for resettlement on an exceptional basis, this tool is in use there and has been

³⁵ WRC, Disabilities Among Refugee and Conflict-affected Populations (June 2008), 41.

³⁶ Interview with official at PSN desk, Nakivale, 3 September 2013.

³⁷ Resettlement Assessment Tool: Refugees with Disabilities (UNHCR, 2013). Available at: http://www.unhcr.org/51de6e7a9.html, accessed 12 December 2013.

valuable in addressing misunderstanding about the suitability of resettlement for refugees with disabilities.³⁸ Resettlement will be discussed in greater detail in section 9.5.

6.2.7 Short-term disability-related projects

At the time of our field-work, UNHCR and its partners had completed short-term disability-related projects using targeted funding, provided for the most part by One Billion Strong, a Qatar-based disability rights organisation. UNHCR and its partners in Nakivale, Oruchinga and Kyaka II refugee settlements received funding to address identified challenges for refugees with disabilities there. They focused on identification, needs assessment and referral systems; access to education; capacity building and empowerment; and access to health and water, sanitation and hygiene (WASH). UNHCR completed a report covering the outcomes of this project.³⁹

Activities included the establishment of associations of refugees with disabilities, both in Kampala and in the settlements, as well as the provision of vocational training and income generation funding; rehabilitation and medical interventions; material assistance to access education; and the construction of dwellings and latrines and the provision of basic household utensils. This funding also supported verification exercises to identify a larger number of persons with disabilities. However, it noted that the ongoing impact of some of the interventions (especially in the area of support for access to education, medical and rehabilitation) rely on ongoing funding.

InterAid directly received a total of 46 million shillings of disability-targeted funding from One Billion Strong. 16 million (approximately US\$4,360) was dedicated to education, 20 million to livelihoods and a final 10 million for rehabilitation expenses. Finally, the Refugee Law Project received 100,000 shillings, which was used to establish its mental health and psychosocial team, as well as implement empowerment activities, including assistance in the development of groups and income generation. It provided its entire staff with disability sensitisation training, and has trained three staff members and 50 refugees in Ugandan Sign Language ⁴¹

Further, in 2011, with the assistance of these organisations, the Women's Refugee Commission carried out research on refugees with disabilities⁴², as well as disability inclusion training. The effects of these pre-existing initiatives were often tangible and presented a contrast with previous fieldwork in other locations, where disability was only just beginning to be a point of focus.

6.2.8 Ongoing initiatives

Some initiatives are ongoing. UNHCR has one staff member whose responsibilities are specifically dedicated to disability inclusion. Likewise, RLP and Interaid Uganda both continue to facilitate meetings of associations of refugees with disabilities, and provide other material and procedural assistance to their beneficiaries.. InterAid has a focal desk for persons with disabilities, has taken steps to make their office physically accessible, and continues to offer reception hours specifically for people with disabilities. Within their budgets, both groups provide material assistance in the form of rehabilitative aids, or access to medical or rehabilitation facilities. Public awareness and advocacy also continue. RLP has a program dedicated specifically to psychosocial support and disability and continues to offer both procedural and material assistance to refugees with disabilities, as well as supporting ongoing advocacy activities.

³⁸ Interview, UNHCR Mbarara, 2 September 2013.

³⁹ UNHCR, One-Billion-Strong Disability Project in Uganda Final Progress Report (May 2013).

⁴⁰ Interview, Interaid Uganda, 12 September 2013.

⁴¹ Interviews, 27 August 2013 and 12 September 2013.

⁴² WRC, Disability Inclusion: Translating Policy into Practice in Humanitarian Action (March 2014); WRC & RLP, "We have a right to love": The Intersection of Sexual and Reproductive Health and Disability for Urban Refugees in Kampala, Uganda (October 2014).

7. Identification

UNHCR officially supports the CRPD and recognises the fundamental importance of the identification of disabilities in ensuring the rights the Convention promotes. It has also taken material steps, including the initiatives outlined above, to bring its operations in line with the CRPD. It is obvious that the identification of persons with disabilities is a prerequisite to being able to design and implement appropriate services and programs to ensure their rights.⁴³

However, as staff interviewed in Uganda observed, the identification of refugees with disabilities remains limited. In its funding proposal to One Billion Strong, UNHCR recognised the importance of disability identification and needs assessment, and emphasised how limited this had been. 44 The list provided to us from the UNHCR database indicated percentages well below international estimates. For example, in Nakivale Refugee Settlement, out of the approximately 66,589 refugees there, only 309 were on record as having disabilities, which equates to about 0.46% of the population.⁴⁵ In Oruchinga, 99 persons, or 1.71% were listed out of a population of 5799. Both these figures are significantly lower than the 15.6% estimated by the World Health Organisation (WHO).⁴⁶

We believe that these low percentages are due to a number of factors. In part, they may be due to the current approach to categorising disability, discussed in the preceding section on ProGres. Further, there appears to be no standard, systematic questions regarding disability which are asked during mainstream registration processes. At registration, people may be visually identified as having a disability, or they may selfreport. UNHCR staff explained that individuals may be motivated to self-report given the assistance benefits that attach to having a disability. 47 Further, they explain that other disabilities, such as hearing or speech impairments, may be identified during the interview, in which each family member is required to at least state their name.

The identification of mental disabilities is particularly challenging. In 2012, there was a psychiatric support mission, which also aimed at capacity building amongst the medical staff. There is one psychiatric nurse in Nakivale. Generally speaking, UNHCR relies on community workers (refugee leaders in the different parts of the settlements) to identify and refer persons with mental illness or mental disabilities, however it is sometimes difficult to discern exactly the nature of the problem. A UNHCR staff member explained:

Sometimes it's just someone who's traumatised by whatever she went through or he we through. Ah, it's also someone who just need maybe a kind of follow up and maybe some assistance and then that person will be fine. Or it is really someone who has like mental disability. So it's really hard.

During verification exercises, persons are referred to the PSN desk for assessment, when vulnerability has already been flagged. Verification is thus a means not only to review existing cases but to identify and assess new ones.48 A number of persons who participated in our group discussions or completed a questionnaire mentioned that they had not been classified as a PSN or an EVI, despite their disability or illness. Others mentioned that the need for documentation to 'prove' they had a disability presented an obstacle, as accessing specialists who could provide such proof generally required material and logistical

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⁴³ For a more detailed discussion and comparison of disability identification across different refugee situations see: Laura Smith-Khan, Mary Crock, Ben Saul & Ron McCallum, 'To "Protect, Promote and Ensure": Overcoming obstacles to identifying refugees with disabilities' (2015) 28(1) Journal of Refugee Studies 38.

⁴⁴ 'Joint proposal (UNHCR – WTU – GIZ – MTI – AHA) of South West refugee settlements – Nakivale/ kyaka II/ Oruchinga, Shafallah Foundation Funding, (undated).

A verification exercise was in its final stages in Nakivale at the time of our fieldwork. The results of the exercise would update this data, and it is

expected that this number would increase.

46 WHO, World Report on Disability, (WHO Press 2011) 27. Note: the WHO percentage refers to 'adults' 15 years and over, so this percentage would be expected to be slightly lower when including younger children. We have an article awaiting publication in the Journal of Refugee Studies which explores in more detail the identification of refugees with disabilities in the four countries we have visited so far, including Uganda.

⁴⁷ Interview, UNHCR Mbarara, 2 September 2013.

⁴⁸ Interview, UNHCR Mbarara, 2 September 2013.

support from UNHCR and its partners first, and this could be difficult to obtain.⁴⁹ Finally, we believe that the stigma associated with certain disabilities and diseases (as well as the experiences that led to their acquisition) may discourage refugees with disabilities from coming forward to self-report.



Image 6: An interview in Nakivale
Photograph: Ben Saul/University of Sydney

However, we also observed promising developments which may have a positive impact on identification. The establishment of an association of persons with disabilities in Nakivale provides an avenue through which refugees can self-organise and act as a referral source. The association's coordinator noted that it is currently comprised of over 200 members. Similar associations have also been established in other locations, including amongst urban refugees in Kampala, generally broken up into country of origin groups.⁵⁰ Refugee community workers in each village within the settlements were also an important source of referrals.⁵¹ In a group discussion, when a participant complained that she had not been put on the list of EVIs, the interpreter explained to her that she should contact her community worker who could follow this up for her.⁵²

Another initiative has been implemented in Kisoro camp, which deals with recent arrivals from the DRC. There, a specific needs desk had been set up in the same room in which registration is conducted. The staff working on this desk were debriefing each day, checking the information included by the registration team against any information regarding specific needs – including disability – which they had identified.⁵³

UNHCR's partners also keep records of their beneficiaries with disabilities. RLP explains that their screening tool includes a disability assessment. This information is entered into SPSS and is analysed every six months.

⁴⁹ Group discussion with urban refugees with disabilities, 12 September 2013.

⁵⁰ Interview, Interaid Uganda, 12 September 2013; Interview, Refugee Law Project, 12 September 2013.

⁵¹ Interview, Interaid Uganda, 12 September 2013.

⁵² Group discussion, Nakivale, 5 September 2013.

⁵³ Interview, UNHCR Mbarara, 2 September 2013.

RLP counsellors can also add qualitative information into the RLP Client Management System. This information can be used to assess needs, as well as assist in the preparation of resettlement submissions. InterAid coordinates monthly case management meetings involving the key stakeholders. This helps with information sharing and referrals between the different organisations.

8. Refugees with disabilities in Uganda

This section will provide an outline of our findings in relation to the incidence of disability amongst refugees in Kampala, Nakivale and Oruchinga. First, we will outline the different types of functional difficulties and pain, fatigue and affect reported by the research participants. We will also discuss the various causes that were identified, including causes related to the displacement context.

8.1 Functional difficulties

In our questionnaire, we ask participants a series of questions about various functions to identify difficulty and assistance needs. For example, we ask 'Do you have difficulty seeing? How much?' and 'Do you have difficulty remembering or concentrating? How much?'. For each area of functioning, we ask 'Do you need assistance with this?' (asking them to specify the type of assistance) and 'Do you have assistance (and is it sufficient)?'. While the research sample was not strictly random, the majority of participants self-identified and thus offer a diverse range of age, gender, nationality and experience. Of the 970 questionnaire participants, 893 had at least some difficulty in one of the functionality areas explored. Of these, 572 reported having a lot of difficulty or not being able to undertake a particular function at all. The table below outlines the number of participants reporting functional difficulties in each of the areas covered. It is important to remember that participants may have multiple functional difficulties.

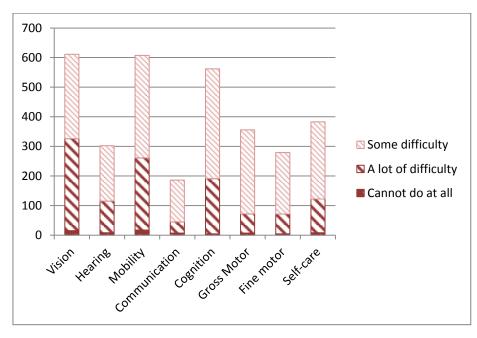


Figure 1: Reports of functional difficulties

8.1.1 Vision

Questionnaire participants were asked 'Do you have difficulty seeing? How much?'. Difficulties with seeing were the most common functional difficulty reported, with more than 62% of participants reporting at least some difficulty. The likelihood of experiencing difficulty generally increased with the age of the participants, with over 72% of those 60 years and above reporting difficulties. This aligns with international research.⁵⁴

For example, WHO observes that disability prevalence is higher amongst the elder sections of society: p 34-5. A recent survey of Syrian refugees in Lebanon and Jordan found the same: HelpAge International & Handicap International, Hidden victims of the Syrian crisis: disabled, injured and older refugees (HelpAge Internation & Handicap International, 2014), 13-14.

Table 3: Reports of difficulties with seeing, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	1	11	2		15
A lot of difficulty	8	34	234	28	7	311
Some difficulty	2	26	233	15	9	285
No difficulty	8	42	196	10	8	264
Unspecified	3	11	70	7	4	95
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	0.88%	1.48%	3.23%	0.00%	1.55%
A lot of difficulty	36.36%	29.82%	31.45%	45.16%	25.00%	32.06%
Some difficulty	9.09%	22.81%	31.32%	24.19%	32.14%	29.38%
No difficulty	36.36%	36.84%	26.34%	16.13%	28.57%	27.22%
Unspecified	13.64%	9.65%	9.41%	11.29%	14.29%	9.79%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

An issue of particular concern was uncovered both during our outreach in the settlements and also in questionnaire responses. Many research participants reported having itchy and watering eyes, which was affecting their sight. This appeared to be caused by the dusty environment and led to allergy and infection that could, in some cases, result in permanent impairment. Such impairments may be avoided through proper hygiene and targeted treatment.

Of the 568 participants who reported needing assistance with their sight, only five claimed to have access to sufficient assistance. 101 said they had had some assistance but that it was not enough and 435 people said that had no assistance. Many participants reported needing glasses. Some identified referral as their needed assistance: a precursor to receiving a diagnosis and treatment. Others had had their eyes tested and had prescriptions but had not obtained any glasses. Others had glasses but they were not the correct strength. Participants describe needs including:

"A place where I can get improved medical care" (Male, 44, Burundi)

"Through being given spectacles or being located in other country that can support my disability" (Female, 54, Burundi)

Some participants described how unaddressed needs related to sight resulted in ongoing pain and discomfort. These unaddressed assistance needs were also identified as barriers in various areas of participation, which will be described in subsequent sections.

8.1.2 Hearing

Participants were asked 'Do you have difficulty hearing? How much?'. Hearing problems were much less commonly reported than problems with seeing. 31.13% of participants reported having difficulties hearing.

Table 4: Reports of hearing difficulties by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	4	3			8
A lot of difficulty	1	13	81	10	2	107
Some difficulty	2	17	155	9	4	187
No difficulty	14	64	369	30	14	491
Unspecified	4	16	136	13	8	177
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	3.51%	0.40%	0.00%	0.00%	0.82%
A lot of difficulty	4.55%	11.40%	10.89%	16.13%	7.14%	11.03%
Some difficulty	9.09%	14.91%	20.83%	14.52%	14.29%	19.28%
No difficulty	63.64%	56.14%	49.60%	48.39%	50.00%	50.62%
Unspecified	18.18%	14.04%	18.28%	20.97%	28.57%	18.25%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

There were some similarities with the needs and causes mentioned by those experience seeing difficulties, and similar experiences of pain related to unaddressed needs:

"I need to be treated as my prescription" (Female, 36, Burundi)

"Medical assistance because of itching and allergy" (Female, 51, DRC)

"A lot of pain: I need special medical assistance" (Male, 51, Burundi)

"I need treatment. I have a lot of pain and blood comes out of one (ear)" (Male, DRC)

Some participants mentioned having developed problems with their hearing due to assaults and other violence:

"My ears have been strongly beaten" (Male, 24)

"(I have had difficulties hearing) since I was attacked" (Male, 39, Burundi)

The identification of hearing difficulties presents some challenges, as these can effectively pass unnoticed. However, UNHCR staff in Mbarara explained that generally, during registration every family member is asked individually to at least state their name. This provides an opportunity for more severe difficulties to be potentially identified, unless they develop at a later point in time.

Refugees with hearing impairments may also face particular challenges in obtaining evidence of their disability. Ugandan National Association of the Deaf (UNAD) representatives in Kampala mentioned that Somali refugees had approached them for assistance during their resettlement submission process, but that they had faced communication difficulties as they used a different sign language. More generally,

documentation requirements proving deafness or other difficulties with hearing were challenging to meet for some of the research participants.⁵⁵

The barriers to participation for those with unassisted and unaccommodated hearing difficulties will be discussed in subsequent sections.

8.1.3 Mobility

Mobility was a major issue identified amongst our research participants. Questionnaire participants were asked 'Do you have difficulty walking or climbing steps? How much?'. 62.57% reported some level of difficulty.

Table 5: Reports of difficulties with walking, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	2	6	8	1		17
A lot of difficulty	8	29	177	21	9	244
Some difficulty	2	28	288	22	6	346
No difficulty	9	37	173	10	9	238
Unspecified	1	14	98	8	4	125
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	9.09%	5.26%	1.08%	1.61%	0.00%	1.75%
A lot of difficulty	36.36%	25.44%	23.79%	33.87%	32.14%	25.15%
Some difficulty	9.09%	24.56%	38.71%	35.48%	21.43%	35.67%
No difficulty	40.91%	32.46%	23.25%	16.13%	32.14%	24.54%
Unspecified	4.55%	12.28%	13.17%	12.90%	14.29%	12.89%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

Difficulties with mobility resulted from the interaction between impairments, diseases and fatigue, with the conditions of life in Uganda. The physical environment in the refugee settlements presents a unique set of challenges. The settlements are located in a remote corner of the country. Distances are substantial. Nakivale itself covers an area of 185 square kilometres. A trip from base camp in Nakivale to the nearest city (Mbarara) takes over one hour in a four-wheel drive, and much longer by other means. Roads are rocky and dusty and there are no footpaths. This creates mobility problems not only for those with physical impairments or injuries. It may also present challenges for persons with vision impairments, those with chronic pain and those who become disoriented.

"(I have problems with mobility) due to my lameness and age" (Male, 72 yrs, Somalia)

"I have had pain that slowly got worse over the past 12 years. I cannot walk now" (Male, 50 yrs, Burundi)

⁵⁵ For example, one participant in the group discussion at Interaid, Kampala, mentioned having failed to obtain documentary evidence from Mulago hospital for his deafness.

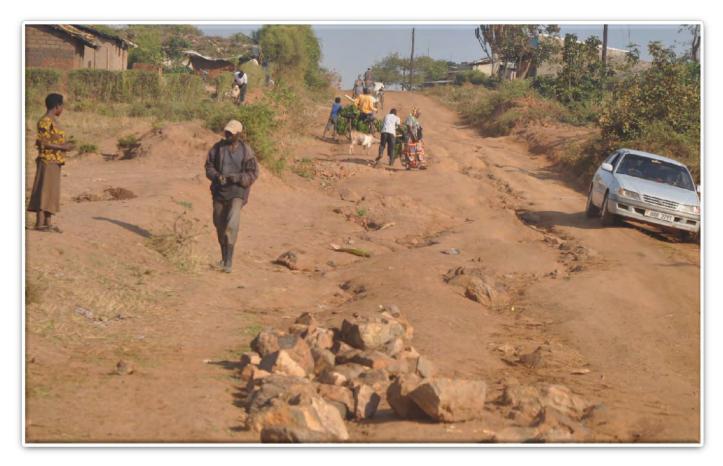


Image 7: Residents navigate a steep, rocky and uneven dirt road in Nakivale Refugee Settlement

Even in Kampala, persons with mobility-related disabilities face many barriers in the built environment, as outlined in a recent study presented by the Ugandan National Action on Physical Disability (UNAPD). According to the results of their recently commissioned survey, a number of important public buildings and markets in Kampala do not meet UNAPD's Accessibility Standards.⁵⁶ On a positive note, InterAid mentioned that it had improved the physical accessibility of its premises by adding ramps to the entrances.

Sometimes participants had received mobility aids, such as wheelchairs, but still faced barriers. For example, a child participant had a wheelchair that did not offer upper-body support, causing him to be hunched in an awkward position. Another man owned two wheelchairs, but was instead crawling, since to use his wheelchair, he relied on his mother to lift him into it and push him around. Service providers noted that on occasion, devices like wheelchairs were valuable assets for families that faced severe poverty, leading them to being sold on so that the family could buy food or other essential items.

8.1.4 Communication

The questionnaire asked participants 'Using the spoken language of your family or ethnic group, do you have difficulty communicating? How much?'. 19.18% of participants reported some level of difficulty. This question was interpreted quite broadly by some participants.

⁵⁶ Kampala Accessibility Status Survey, presented 28 August 2013: see http://unapd.org/

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Table 6: Reports of communication difficulties, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	5	1			7
A lot of difficulty	2	13	17	2	4	38
Some difficulty	3	15	117	5	1	141
No difficulty	13	63	448	40	14	578
Unspecified	3	18	161	15	9	206
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	4.39%	0.13%	0.00%	0.00%	0.72%
A lot of difficulty	9.09%	11.40%	2.28%	3.23%	14.29%	3.92%
Some difficulty	13.64%	13.16%	15.73%	8.06%	3.57%	14.54%
No difficulty	59.09%	55.26%	60.22%	64.52%	50.00%	59.59%
Unspecified	13.64%	15.79%	21.64%	24.19%	32.14%	21.24%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

On closer inspection, the variety of explanations accompanying responses to this question provides an interesting example of how the manner of asking a question can significantly impact on the responses received. While some of the participants linked communication difficulties with speech, hearing impairments or cognitive impairments, others interpreted this question quite differently.

For those persons who had communication difficulties related to impairments, their family members reported difficulties in responding to other questions in the questionnaire. For example, some were unable to say whether (or how often) their family member experienced pain, or felt anxious or depressed. This is an example of how lack of assistance to overcome one particular functional difficulty can impact on the identification, assessment and accommodation of other difficulties.

This may also be true for those experiencing communication difficulties for other reasons. Many participants ignored the element of the question referring their ethnic language and identified difficulty in communicating due to a lack of knowledge of the local regional language or English (and limited education opportunities more generally). This issue reappeared throughout the questionnaire, as a common barrier to accessing various services or reporting needs or protection concerns. The inability to effectively communicate in the displacement context was an important issue for many participants.⁵⁷

"I cannot raise up my voice because it requires energy" (Female, 50, Somalia)

"He does not understand nor speak comprehensibly. I want help which can help him to study and feel good with his friends" (Male, 7, DRC)

Finally, some participants explained that they experienced communication difficulties due to a lack of opportunities to learn or speak their ethnic language in the displacement context, while others reported having been denied this opportunity before fleeing their country of origin, with language closely linked to ethnic discrimination and expectations by majority groups that minorities speak a majority language. For these participants, lack of access to their ethnic languages was thus a denial of rights and represented an element of their social exclusion or discrimination.

⁵⁷ Communication issues and suggested responses are discussed in Calisto Mudzingwa, 'KiSwahili: the lingua franca of Nakivale Refugee Settlement in Uganda' (2011) 5(2) Sociolinguistic Studies 347.

8.1.5 Remembering and concentrating

Difficulties with remembering and concentrating were common, being reported by 57.94% of questionnaire participants.

Table 7: Reports of cognitive difficulties, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all		1	3			4
A lot of difficulty	2	24	148	9	4	187
Some difficulty	1	27	316	21	6	371
No difficulty	14	44	168	19	10	255
Unspecified	5	18	109	13	8	153
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	0.00%	0.88%	0.40%	0.00%	0.00%	0.41%
A lot of difficulty	9.09%	21.05%	19.89%	14.52%	14.29%	19.28%
Some difficulty	4.55%	23.68%	42.47%	33.87%	21.43%	38.25%
No difficulty	63.64%	38.60%	22.58%	30.65%	35.71%	26.29%
Unspecified	22.73%	15.79%	14.65%	20.97%	28.57%	15.77%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

This has serious implications for the processing of refugee claims and settlement interviews. Many participants attributed these difficulties to the trauma they had experienced before (and sometimes after) leaving their countries of origin.

Participants identified various assistance needs associated with this difficulty. Many requested 'medical treatment', diagnosis, medicine or psychosocial assistance. Some believed that if their living conditions were better (for example, through resettlement, better security, nutrition or a larger home), they would be able to forget their trauma and improve their cognition. Examples of the needs identified included:

"If I get something to make me happy my remembering may improve" (Male, 43, Somalia)

"I need assistance. If I get a good future I will become okay. When I feel stress I become forgetful." (Male, 28, Somalia)

"I need psychosocial service and where I can be safer" (Female, 30, Burundi)

This demonstrated that participants understood a clear link between trauma and mental health issues and cognitive ability. These responses indicate that they believed that if their mental health issues could be addressed, their cognitive functionality would improve.

8.1.6 Gross motor

Questionnaire participants were asked 'Do you have difficulty raising a 2L bottle of water from waist to eye level (gross motor functioning)?'. 36% reported having some level of difficulty with this.

[&]quot;Treatment and a balanced diet" (Female, 35, Burundi)

[&]quot;I need counselling - my parents were shot to death" (Female, 38, DRC)

Table 8: Reports of gross motor difficulties, by age group, as numbers and as percentages of age groups

Difficulty level	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	3	3			7
A lot of difficulty	3	16	38	5	3	65
Some difficulty	4	30	220	22	8	284
No difficulty	8	48	321	18	9	404
Unspecified	6	17	162	17	8	210
Total	22	114	744	62	28	970

Difficulty level	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	2.63%	0.40%	0.00%	0.00%	0.72%
A lot of difficulty	13.64%	14.04%	5.11%	8.06%	10.71%	6.70%
Some difficulty	18.18%	26.32%	29.57%	35.48%	28.57%	29.28%
No difficulty	36.36%	42.11%	43.15%	29.03%	32.14%	41.65%
Unspecified	27.27%	14.91%	21.77%	27.42%	28.57%	21.65%
Grand Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

While severe difficulties were more common amongst younger participants, more than a third of adults reported at least some difficulty with using their arms, undermining their ability to cultivate their land and collect food and water, as well as earn an income (given limited employment options), making them more dependent on others. Some experienced problems with gross motor which were related to impairment or illness is other places in their body, which had not been properly addressed.

"I rely on my neighbours to collect food for me. The food is not enough. i just eat once in the morning. It should be twice as much" (Male, 50 yrs, Burundi)

"It is hard to lift things with one leg/crutches" (Female, 13 yrs, DRC)

This demonstrates the interconnectedness of different impairments, and how when one area is not addressed, this may have a greater impact than imagined. Being unable to collect one's own food not only undermines agency and inclusion, it may also have an impact on nutrition. Likewise, a mobility impairment that is not properly accommodated or addressed can have an impact on the ability to use one's arms.

8.1.7 Fine motor

Difficulties with fine motor (use of the fingers) were reported by 28.76% of participants.

While some fine motor problems were related to congenital disabilities, or conditions like arthritis, a number of participants describe experiencing torture and other violence which has impacted their fine motor, either directly through injury to the fingers and hands, or through injuries to other parts of their body that have affected their nerves.

Such impairments do not only affect functioning, but can also become a focus of discrimination and social isolation, as explained by one participant:

"People jeered at me, they insult me by saying I don't have fingernails and I am trauma" (Female, 31 yrs, DRC)

Table 9: Reports of fine motor difficulties, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	1	2			4
A lot of difficulty	4	14	42	6	1	67
Some difficulty	1	17	170	14	6	208
No difficulty	10	62	391	26	13	502
Unspecified	6	20	139	16	8	189
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	0.88%	0.27%	0.00%	0.00%	0.41%
A lot of difficulty	18.18%	12.28%	5.65%	9.68%	3.57%	6.91%
Some difficulty	4.55%	14.91%	22.85%	22.58%	21.43%	21.44%
No difficulty	45.45%	54.39%	52.55%	41.94%	46.43%	51.75%
Unspecified	27.27%	17.54%	18.68%	25.81%	28.57%	19.48%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

8.1.8 Self-care

A question asking participants whether they had difficulties with self-care was interpreted rather broadly, with nearly 40% of participants reporting difficulties. This is one of the challenges of relying on self-administered questionnaires.

Table 10: Reports of fine motor difficulties, by age group, as numbers and as percentages of age groups

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	1	3	3	1		8
A lot of difficulty	5	19	78	9	3	114
Some difficulty	5	27	205	20	4	261
No difficulty	6	42	306	16	11	381
Unspecified	5	23	152	16	10	206
Total	22	114	744	62	28	970

Level of difficulty	0 to 4 years	5 to 17 years	18 to 59 years	60 or above	Unspecified	Overall
Cannot do at all	4.55%	2.63%	0.40%	1.61%	0.00%	0.82%
A lot of difficulty	22.73%	16.67%	10.48%	14.52%	10.71%	11.75%
Some difficulty	22.73%	23.68%	27.55%	32.26%	14.29%	26.91%
No difficulty	27.27%	36.84%	41.13%	25.81%	39.29%	39.28%
Unspecified	22.73%	20.18%	20.43%	25.81%	35.71%	21.24%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

This broader interpretation encompasses participants who regard their living situation as precarious, identifying issues like the inability to earn sufficient income and support oneself and one's family as a difficulty with self-care. In some cases this related specifically to the materials needed to dress and wash, such as soap and clothes (rather than the physical ability to dress and wash). Others did, however, identify the difficulties they faced with daily activities like dressing and washing themselves. Many relied on assistance from family members.

"Because I am disable, I can't dress on myself so I need medical assistance" (Male, 9 yrs, Somalia)

"(The assistance I need is) getting clothes and soap" (Female, 13 yrs, Burundi)

"When (her) back hurts or when dizzy, she has trouble washing. Her children help her when they are not at school." (Female, 48 yrs, DRC).

8.2 Pain, fatigue and affect

The questionnaire included questions about pain, fatigue and affect (nervousness, anxiety and depression). It explored causes, as well as asking whether participants had resources to overcome these issues.

8.2.1 Pain

Nearly half of all participants reported experiencing pain every day, and a further 18% said they experienced pain most days. Many participants claimed to have no access to pain killers or other forms of pain relief. Pain, left unaddressed, can contribute to functional difficulty, undermining a person's ability to undertake daily activities.

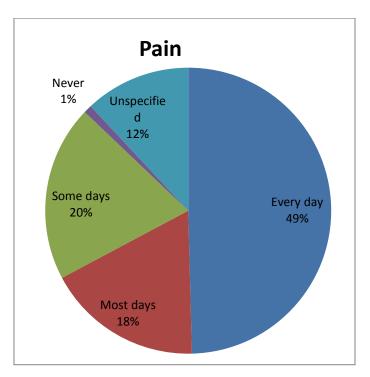


Figure 2: Reported frequency of pain

For many participants, pain related to their disability. In many cases, it more specifically resulted from injuries or illnesses that had not been adequately treated, or for which assistance had been less than ideal. For example, many participants had internal injuries and infections as the result of sexual violence that had not been treated which, in some cases, caused constant pain and discomfort.

"I still have two bullets in my leg - they cause me pain" (Male, 44, Somalia)

"Even though we have had to flee and people were shooting at us with guns, still there is no medical assistance" (Male, DRC)

"My finger was cut and they harmed... my foot and they raped me, since at the moment nothing done" (Male, 31, Burundi)

"His leg rubs against the prosthesis and he experiences back pain from walking" (Male, 23, DRC)

Others attributed their pain partly to living conditions in displacement. Having to walk long distances, the type of work available to refugees, and diet limitations all interacted with participants' impairments and illnesses to cause them pain.

"I am always pain when am working to survive and it hurts my back and my legs" (Female, 58, DRC)

"It is because of eating foods who don't have vitamins, it hurt in the stomach" (Female, 13, DRC)

"In legs. My pain gets worse when I use the sewing machine. The doctor has advised me not to use it." (Male, 32, DRC)

For some participants, pain was linked with trauma and psychosocial difficulties.

"Because the thing that we live in DRC like seeing the way the rebels kill my father and other in family give me headache and be traumatised in my life" (Male, 33 DRC)

"My pain is caused by thinking a lot of thing from the bad life" (Female, 44, Burundi)

"As a result of violence, it hurts me in the mind" (Female, 20, DRC)

While much could be done to eliminate the experiences of pain described above by addressing the root causes, even access to pain killers was limited. A number of participants explained how they had had access to pain killers for a period of time, but had now stopped receiving them, presumably due to limited stocks.

8.2.2 Affect

Along with difficulties with memory and concentration, this question acted to flag potential psychosocial difficulties. Nearly 80% (774) of participants reported experiencing anxiety, nervousness or depression at least some days. Only 5% claimed to never experience this. This is in line with another recent study on disability – amongst Syrian refugees in Lebanon and Jordan – in which psychological distress was reported twice as often amongst persons with disabilities than the overall refugee population.⁵⁸

⁵⁸ HelpAge International & Handicap International, *Hidden victims of the Syrian crisis: disabled, injured and older refugees* (2014).

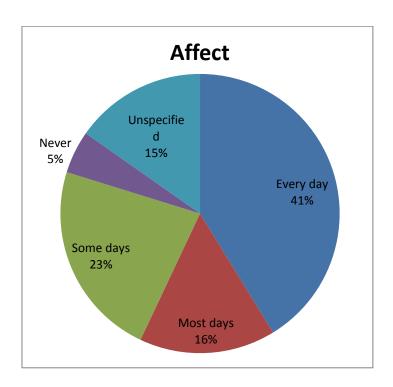


Figure 3: Reported frequency of anxiety, depression and/or nervousness

The main causes of anxiety, depression and nervousness were trauma related to experiences in participants' countries of origin and general problems in their current situation.

"Torture and segregation from the neighbours, which lead me recalling all the bad things that happened to me" (Male, 49, Burundi)

"I often dream people are coming to rape me. I remember (what) I was feeling before the rape and after it. I am asking myself who is the father of that child (born of rape)" (Female, 34, Burundi)

"It (is) caused by the stress of life in the camp" (Female, 23, Rwanda)

Disability and the many barriers to full participation were another significant identified cause of anxiety, depression and nervousness.⁵⁹

"The feeling of loneliness among other children and feeling nervous worsens the situation" (Female, 6, Rwanda)

"I am a single mother with orphans, lack of proper medical care, lack of enough foods, and long over stay in the camp without resettlement" (Female, 46, Somalia)

8.2.3 Fatigue

Many participants reported regularly feeling fatigued. They attributed this to a variety of causes, including difficult work and living conditions, nutrition, illness, stress and depression, lack of sleep (sometimes linked with psychosocial difficulties) and pain.

⁵⁹ Similarly, the report on Syrian refugees indicated that the main causes of psychological distress amongst refugees with specific needs included

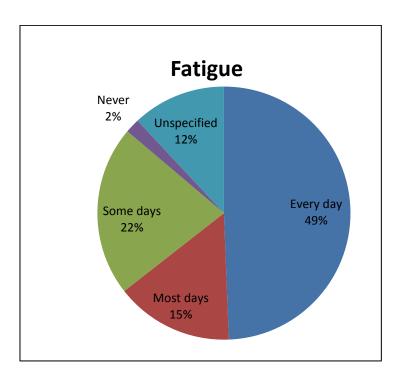


Figure 4: Reported frequency of fatigue

"If I walk too much I get tired. When I get stomach problems, I can't sleep - this also makes me tired" (Male, 21, DRC)

"I get tired because of heavy works that I do, I don't have anyone to help me" (Female, 20, DRC)

"Since I am a single mother all home activities I am the one doing and most of my children are ill and I was also raped. A lot of work and staying in bad life" (Female, 35, South Sudan)

8.3 Acquisition

The questionnaire explored disability acquisition, asking participants to identify the cause of their impairment, and their location and age when they acquired it. This proved a challenging question to answer and to code, as many participants were struggling with multiple challenges in their lives. For example, an impairment they acquired in their home country may have been exacerbated by living conditions in displacement, or they may have been injured and traumatised during conflict, but have since had a traffic accident in Uganda. The question "how did you acquire your disability" received the following responses.

68 participants listed more than one cause. Taking into account this extra information, 'attack or violence' was listed as a cause of disability for a total of 489 – or just over half – of all participants. Many people used the 'Other' free text box to add the secondary cause. Some also listed war or conflict in the 'Other' box, which was recoded to fall within the 'attack or violence' category.

While we touched upon common causes for particular functional difficulties earlier, we will explore each of the acquisition categories in more detail below, highlighting some themes that emerged from the research.

Table 11: Reports of cause of disability, including extra responses

Disability cause	Disability cause response count	Total count including secondary responses
Accident	61	76
Attack/violence	454	489
Congenital/inherited	49	
Disease/illness	270	
Other	32	
Unspecified	104	
Total	970	

8.3.1 Accident

Including secondary responses, a total of 76 participants listed accidents as a cause of disability acquisition. While many participants (56) did not provide information about the type of accident they had experienced, the most common type mentioned was transport-related accidents (10). Three participants mentioned having accidents (eg 'falling down') while fleeing persecution in their home country. Two mentioned accidentally receiving burns and another two identified medical negligence ('bad injections') as a cause of disability. Participants in group discussions also mentioned traffic accidents in Uganda as a cause of disability acquisition.

8.3.2 Attack or violence

Just over half (489) of the participants listed attacks or violence as a cause of disability acquisition. While no questions were asked specifically about sexual violence, this was a serious issue that emerged for both male and female participants, although it was not always listed in response to the acquisition question, but rather often emerged in other places in the questionnaire. Despite not asking any direct question to that effect, the questionnaire uncovered 238 reports of sexual violence. While much of the sexual violence mentioned related to incidents in participants' countries of origin or when fleeing, around 10-15% were identified as reports of sexual violence occurring in Uganda. Further, a number of group discussion participants reported sexual violence occurring during their time in Uganda. Survivors of sexual violence faced a wide range of difficulties, including physical impairment, infection and chronic disease, as well as psychosocial difficulties and discrimination. for the participants reported to the participants of the participants are possible to the participants of the participants are possible to the participants are provided as a participant of the participants are participants.

8.3.3 Congenital or inherited

Congenital or inherited disabilities accounted for a small proportion of the causes reported. These were connected with reports of discrimination against not only the persons with disabilities, but also their family members – most commonly their mothers. Some mothers reported being abandoned by their husbands or their in-laws, who blamed them for giving birth to a child with a disability. This withdrawal of family support, accompanied by the emotional damage created by such an accusation, undoubtedly creates greater difficulty for persons with disabilities and, where applicable, their mothers.

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⁶⁰ This included 182 reports of having experienced sexual violence personally, or witnessed attacks on close family. A further 56 were suspected reports of sexual violence that were ambiguously expressed. There were 28 clearly-worded and 19 ambiguously-worded reports of sexual violence in Uganda. For a more detailed exploration see Laura Smith-Khan, Mary Crock, Ron McCallum & Ben Saul, "Up to now I am suffering": Justice, sexual violence and disability amongst refugees in Uganda' (2015) 1(4) *International Journal of Migration and Border Studies* 348.

⁶¹ More discussion on women's and girls' experiences of sexual violence, abuse and exploitation in Uganda is included in Refugee Law Project (2014) From the Frying Pan into the Fire: Psychosocial Challenges Faced by Vulnerable Refugee Women and Girls in Kampala; (2011).

8.3.4 Disease or illness

As will be further discussed in section 10, below, disease and illness was a significant issue for many participants, and caused all types of functional difficulties. It was sometimes caused by and sometimes affected food consumption (as in the case of recurring stomach ulcers). At other times, diseases were contracted as a result of violence, for example, HIV contraction. Limited access to adequate treatment and clean water also exacerbates or creates disease and illness. Climate and the dusty environment were also triggers for conditions like asthma.

9. Protection and durable solutions

9.1 Protection issues in Uganda

Our fieldwork uncovered a number of protection-related concerns for refugees with disabilities. These generally echo the observations and recommendations of existing research.⁶²

Distance to facilities increased vulnerability: while some refugees with disabilities had been allotted plots in the Base Camp areas of the settlements, and thus had support close at hand, this was not uniform across the large group of vulnerable people with whom we came into contact. Many of our research participants lived in isolated areas of the settlements, at a distance from Base Camp and available services. Women and children collecting firewood and water at a distance from their homes and built up areas reported being vulnerable to attacks. Even where water points were relatively close, the water supply from the taps was limited, meaning that many resorted to travelling great distances to collect water from the swamps or lake.



Image 8: A woman collects firewood in Nakivale Refugee Settlement

In one case, land was donated and homes constructed for a group of particularly vulnerable people, including some who had disabilities. While there was a water point and food distribution close by, these houses were at a great distance from Base Camp. It also seemed problematic to place a group of persons, who were all classified as vulnerable, together in one place.⁶³

As discussed, there were many reports of sexual and physical abuse amongst both questionnaire and discussion group participants. In some cases this abuse was ongoing. Others had filed reports, but feared retribution, as they continued to live in vulnerable situations, close to their attackers. For others, fear relating to protection concerns carried over from their country of origin. One participant explained:

"He told someone about his experience and that person told others. He now fears that others will find and attack him. People talk about him and it makes him feel scared" (Male, 28, Burundi)

RLP has done several studies related to the protection needs of refugees with disabilities living in Uganda, focusing on specific themes and providing a strong foundation on which to develop appropriate responses. For example: Refugee Law Project (2014) From the Frying Pan into the Fire: Psychosocial Challenges Faced by Vulnerable Refugee Women and Girls in Kampala; (2011) 'Gender Against Men' (documentary) https://www.youtube.com/watch?v=mJSl99HQYXc&list=UUa_pj7eKirDHdEkoc_mxOnw; (2011) 'They Slept With Me' (documentary) https://www.youtube.com/watch?v=6dxaFqezrXg&index=36&list=UUa_pj7eKirDHdEkoc_mxOnw.

⁶³ A similar observation was made in a review of Syrian refugees in Iraq: Janet Njelesani & Shirin Kiani, 'Rapid Needs Assessment: Situation of children, youth and adults with disabilities, within and around Domiz, Northern Iraq' (Handicap International & Unicef, December 2013), 8.

Similar protection issues were prevalent in the urban refugee community. In one case, the wife of a man with a severe disability explained that since she was a full-time carer for her husband, she was unable to work or take care of her children, who spent their time out on the streets and had experienced serious assaults.

Unaccompanied vulnerable persons, including unaccompanied youth with disabilities, recounted their experiences of living with families who had either 'adopted' them or employed them and experiencing ongoing abuse from members of their host family. Since they had nowhere to go and nobody to support them, they had no choice but to remain in these abusive environments.

Responses by authorities include the transfer of persons from one settlement to another when they are deemed particularly in danger:

"Yes, on the basis of my tribe and I was even transferred from Oruchinga to Nakivale to get better security, which I still cannot access. Due to discrimination my house was destroyed with them and one of my family was killed and I have written investigation of the police" (Male, 32, Rwanda)

A variety of initiatives are being implemented addressing general protection issues. For example, UNHCR and the Ugandan Government (along with assistance from the Refugee Law Project and the Uganda Human Rights Council) are piloting a mobile court in Nakivale, to deal with crime there. It is hoped that this will act as a deterrent and lead to a decrease in crime. Similarly, UNHCR is working on improving the availability of alternative fuels for cooking (to decrease the need for firewood collection in isolated areas)⁶⁴ and is erecting solar-powered lights.

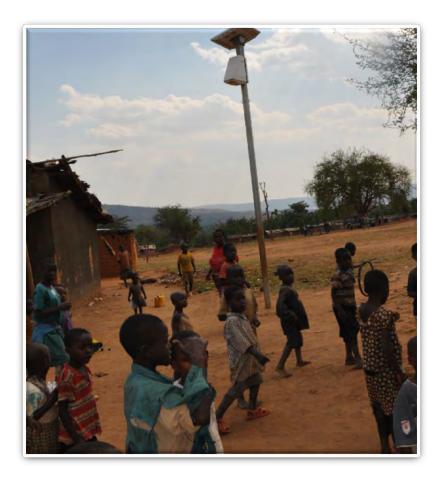


Image 9: Refugee children gather around a solar-powered light

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⁶⁴ UNHCR (2013) 'Innovation: Briquette-making project helps protect women in Ugandan camp', http://www.unhcr.org/520500559.html, 9 August 2013 and UNHCR (2013) 'Mobile court scheme launched in Uganda's Nakivale refugee settlement', http://www.unhcr.org/print/516d29359.html, 16 April 2013.

9.2 Refugee Status Determination

In Uganda, the government is primarily responsible for refugee status determination (RSD), with technical and logistical assistance from UNHCR. While those refugees who arrive in groups as part of 'mass influxes' are generally given refugee status *prima facie*, those who present themselves to the authorities individually have their claims assessed by the Refugee Eligibility Committee (REC).⁶⁵ One particular concern is the accommodation of persons experiencing psychosocial difficulties. If these difficulties are not identified nor properly accommodated, this could impact on the ability of asylum seekers to tell their story, and could undermine credibility assessments.⁶⁶

9.3 Local integration

Uganda is considered a generous refugee host country. It is a signatory of the Refugee Convention and Protocol and allows refugees to enter and stay in Uganda indefinitely. Although refugees officially have freedom of movement, those living in the settlements must apply for an exit permit on each occasion they wish to leave. There are no permanent exit permits from the settlements, although asylum seekers have the option to register as refugees and live in Kampala. 88

At present, refugees do not have access to citizenship in Uganda (beyond those avenues open to other foreigners, such as marriage to a Ugandan national). ⁶⁹ While barriers to citizenship present challenges for all refugees, they may have specific implications for refugees with disabilities. For example, any rights or benefits accorded under Uganda law to Ugandan citizens with disabilities may not be officially available to non-citizen refugees.

In practical terms, there are many barriers to the full and effective local integration of refugees with disabilities. These are reflected in the contents of this report as a whole, and more specifically, the sections on humanitarian assistance, participation and protection.

9.4 Repatriation

Talk of cessation and the need for Rwandan refugees to repatriate had reportedly caused some difficulties for some participants. This included reports that various service providers were withholding assistance to Rwandans, such as the claim below:

"At Mbarara hospital, when I started to explain my problem of fracture, a doctor asked me: are you Rwandese refugee? I replied yes. He told me that the specialist is not available and that I will be treated in my country after the invocation of cessation clause. I replied that I am not in the category concerned by this, that I can be helped like others" (Male, 20, Rwanda)

Refugees with disabilities may face additional challenges during and after repatriation. These would need to be taken into account, and programs to facilitate reintegration would need to accommodate persons with disabilities, to ensure successful voluntary return, where this is deemed a suitable durable solution.⁷⁰

⁶⁵ Interview, UNHCR Kampala, 26 August 2013.

⁶⁶ Mansha Mirza, 'Disability and cross-border mobility: comparing resettlement experiences of Cambodian and Somali refugees with disabilities', (2011) 26(5) *Disability & Society* 521, 529.

⁶⁷ UNHCR, '2014 UNHCR Country operations profile – Uganda', http://www.unhcr.org/pages/49e483c06.html.

⁶⁸ Interview, UNHCR Mbarara, 2 September.

⁶⁹ Critique of the Refugees Act (2006) (Refugee Law Project, 21-3. The Refugee Law Project, UNHCR and other partners are currently involved in contesting in court the barriers to citizenship for refugees in Uganda.

⁷⁰ The potential for barriers to successful repatriation for refugees with disabilities is an issue which is mentioned in UNHCR's Resettlement Assessment Tool for refugees with disabilities.

9.5 Resettlement

When neither local integration nor repatriation are suitable options, resettlement becomes the suitable durable solution. Given the shortcomings of local integration and repatriation for certain refugees with disabilities, resettlement becomes imperative. Yet there are many challenges to ensuring inclusive resettlement, as highlighted by a UNHCR staff member:

"You know as someone who's moving on his elbows and knees, here people would say, oh this person cannot make it in Europe, but that's the total opposite. That person can become very independent and very autonomous and function very well in a place where there's sidewalks and proper wheelchairs..."

This quote indicates the shortcomings of focusing on a person's impairment, rather than their environment. What this officer realises and has sought to imbue in her colleagues is that when the focus shifts to the barriers a person faces and which may be overcome in a different setting, the potential benefits of resettlement for refugees with disabilities become obvious.

Staff in Mbarara had observed that very low numbers of people with disabilities were being referred for resettlement by other units. It came out that the officers thought that persons with disabilities would not be able to manage in resettlement, so they should not be referring them. However, the officer with whom we spoke explained that she had worked hard to try and address these misconceptions.

While resettlement is not the recommended durable solution for all refugees in Uganda, it is used for persons who face barriers to effective local integration or repatriation. This includes some refugees with disabilities. The resettlement unit have been using the specialised Resettlement Assessment Tool. Most submissions including persons with disabilities are being submitted to the US, where there is a lot of support available (especially for physical disabilities) and which has a more inclusive resettlement policy than other countries (for example, Australia). UNHCR have worked with field staff to try to sensitise them about the inclusion of refugees with disabilities. They have submitted resettlement cases for persons with disabilities under the various resettlement categories, recognising that, the same as anyone else, persons with disabilities can have a variety of experiences that merit resettlement.⁷²

Staff identified persons with mental disabilities and mental illness as presenting the greatest challenge in resettlement, as resettling countries shared concerns regarding the impact of resettlement on families. They gave the example of a single mother with a mental disability who had been the victim of rape on more than one occasion in the settlement. Due to laws in the resettling country, her children were likely to be removed from her on arrival and there was concern over whether this was the best outcome for all involved. They noted that submissions where persons with disabilities had strong family support were generally more successful, meaning that those like the woman given in the example, faced challenges in gaining access to a suitable durable solution.⁷³

The Refugee Law Project is also involved in referring persons with disabilities for resettlement. They noted that these cases presented challenges, and that a group of refugees with disabilities that had been submitted for resettlement in 2011 was still awaiting an outcome.⁷⁴

DPOs have also been involved in assisting with resettlement submissions. For example, the Ugandan National Association for the Deaf has provided recommendation letters for Somali refugees.

⁷¹ Interview, UNHCR Mbarara, 2 September 2013.

⁷² Interview, UNHCR Mbarara, 2 September 2013.

⁷³ Interview, UNHCR Mbarara, 2 September 2013.

⁷⁴ Interview, Refugee Law Project, 27 August 2013.

10. Humanitarian assistance

10.1 Food and nutrition

Nearly half (450) of all questionnaire participants claim to have one meal or less per day. Only ten reported having three or more meals.

Table 12: Reports on number of daily meals consumed

Meals per day	Response count
0-1	11
1	439
1-2	5
2	176
3	10
Unspecified	329
Total	970

When asked about barriers to accessing food, the most commonly identified problem was quantity: the food available through WFP rations was insufficient. Interconnected with this, many participants claimed that due to their disability or illness, it was difficult for them to cultivate their land to supplement their diet. Further, they had limited options for income generation, limiting their ability to buy food. One participant mentioned that she was engaged in survival sex, being paid in food, to support her family. For some families, lack of food was a reason some children did not attend school.

"I have a disability so I am not able to cultivate or dig to get enough food and yet I get little food from the World Food Program which cannot feed me for the whole month." (Female, 26, DRC)

"We only receive food rations. I cannot supplement this because I cannot work. My children do not receive any food at school either." (Female, 34, DRC)

Other major obstacles include distance and mobility and other issues related to the collection of food rations, including crowded distribution points. On a positive note, some participants mention being allocated land in the Base Camp area in order to be close to facilities, including food distribution. UNHCR also encourages community members to mobilise to support those people who cannot collect their own food. They noted that those with strong family networks are likely to receive better assistance.⁷⁵

"...my injuries prevent me from travelling long distances to obtain and carry food. I would like to be able to transport it" (Male, 32, DRC)

"The big problem that I face to carry on the head make my head to pain and where get food is far from where I live" (Male, 33, DRC)

"We wait a long time from morning to evening. When I stand a long time, I become very tired because of my two legs" (Male, 20, Rwanda)

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⁷⁵ Interview, UNHCR Mbarara, 2 September 2013.

Food quality was also identified as an ongoing problem for many participants. Many mention having ulcers or other diet-related conditions. These conditions have the effect of restricting the types of foods the person feels comfortable eating.

Finally, participants identified barriers to food preparation, such as a lack of access to water, firewood (or other fuel sources) and cooking utensils. Others had difficulties preparing food due to their disabilities, including those with sight impairments or issues with gross or fine motor, when they did not have family or other persons to assist them.

"I only have supper. There is no charcoal, stove and other objects to use. There is not much money to buy vegetables. I normally take posho and beans" (Male, 24, DRC)

"The food we are given isnt enough as we can't even cook it as we don't have wood, also we don't have the cooking utensils" (Parent of female, 3, DRC)

"I cannot cook for myself, I have to wait until someone helps me" (Female, above 60, Burundi)

10.2 Water, Sanitation and Hygiene

Table 13: Reports regarding access to sufficient water

Access to enough water	Response count
Yes always	54
Most of the time	72
Sometimes	475
Never	243
Unspecified	126
Total	970

The majority of questionnaire participants reported not having regular access to enough water. This can have implications for hygiene, food preparation and the prevention and treatment of infection. As well as quantity, water quality was a concern, with many participants supplementing water from access points with water from swamps and lakes. Severe skin infections and intestinal diseases were common complaints, many of which may have been related to water quality.

"The water is not safe. I need water which is safe because water is life" (Female, 51, DRC)

"I have access to water always, but with risk of disease because it is not well treated (treatment time not long enough) (toxic for kidneys and genital organs). Also, access to water - only strong persons pass the first" (Male, 55, Rwanda)

Related problems included increased vulnerability to assault during trips to collect water, which sometimes involved travelling long distances, through isolated areas. Female group discussion participants all agreed that collecting water was a challenge. They noted that it was usually them or their children who were the ones to collect it.

"I am scared to go out alone to collect water - I am scared I may be tortured or sexually abused" (Female, 23, DRC)

Many participants were unable to collect the water due to difficulties with mobility, the distance or the ability to carry jerry cans. On a positive note, one participant explained how a 'good Samaritan' had given him a bicycle that allowed him to transport water and overcome his difficulties with mobility.

"When I go to fetch water, I (can't) access the water because nobody is there to (physically support me). When we are asked to (form) a line (to receive food or water), because I am weak, I can't access first position or place" (Male, 18, Burundi)



Image 10: Young women in Oruchinga Refugee Settlement carry jerry cans of water

10.3 Shelter

Some participants who had been identified as EVIs had had shelters built for them. UNHCR receives earmarked funding each year to construct shelters for vulnerable persons. Groups of refugees – generally men – construct these shelters. Others participants reported receiving allotments close to facilities to help overcome mobility difficulties. Still, many participants identified distance as a major obstacle in various aspects of their life, including access to food and water. This created a reliance on others to assist in collecting and delivering food, water and other goods. At times, participants explained that if their neighbours did not bring

⁷⁶ Interview, UNHCR Mbarara, 2 September 2013.

them food, they would not be able to eat. Some relied on others to build or repair their homes. One female participant mentioned that while community builders were supposed to repair her home, their wives prevented them, as they knew she was a single woman. Finally, some participants claimed to have no home or land. A few said that they had been chased out of their home and had their land and home taken by others.



Image 11: A shelter with UNHCR plastic sheeting in Nakivale Refugee Settlement

A common request in group discussions was for new plastic sheeting from UNHCR, to prepare for the coming raining season and a common complaint was the size and quality of homes. A number of participants complained that their overcrowded homes contributed to their memory and concentration problems.

10.4 Health and rehabilitation services

Health and rehabilitation needs were one area of focus in recent targeted activities, using One Billion Strong funding, through which medical intervention and rehabilitation was provided to a group of identified refugees with disabilities. Needs assessments related to disabilities are effectively divided across separate organisations, based on the type of needs. MTI conducts health and rehabilitation related needs assessments, while community services-related assistance assessments are carried out by other organisations.

The major challenges we identified included:

- Access to appropriate health care
- Rehabilitation
- Pain management
- Psychosocial health
- Health literacy

Many cases of serious medical and rehabilitation needs were identified, including suspected cases of fistula

and trachoma which, without urgent treatment, could lead to serious permanent impairment. Again, the physical isolation of many of the refugees in the settlement and the challenges they face in travelling to seek appropriate assistance was a major issue. There is an urgent need for targeted missions to the various areas of the settlements to address such serious and pressing medical concerns.

Psychosocial support was an outstanding need for many people. Many of the refugees had experienced high levels of trauma and torture, mainly in their home countries. There seemed to be little available support for their psychosocial needs. UNHCR staff noted that there is one psychiatric nurse covering the whole of Nakivale. This leads to an environment in which people with unaddressed psychosocial problems are interacting with each other, potentially exacerbating their existing conditions and leading to renewed violence. Organisations like the RLP and Interaid Uganda offer counselling and psychology services for refugees. RLP also holds events and has helped establish self-help groups for survivors of sexual violence which are helpful not only in terms of addressing trauma, but also in building awareness and combatting stigma and discrimination.

Many of the refugees with whom we spoke had been experiencing long-term chronic pain, mainly due to serious conflict-related injuries they had sustained in their home countries and for which they had not been able to access sufficient treatment or assistance. However, access to painkillers was inconsistent and many lacked the necessary support to properly manage their pain.

The need for a referral and the cost of transport to attend hospitals or rehabilitation centres presented barriers for many participants. Some noted that although they were able to attend an initial consultation at a hospital, once there, the required doctor was unavailable or they were asked to come back for a review. This was challenging, as they would have to go through the process of seeking a referral from the health centre and then obtaining official government permission to leave the settlement, and also overcome the practical and financial challenges to travel to attend these appointments.

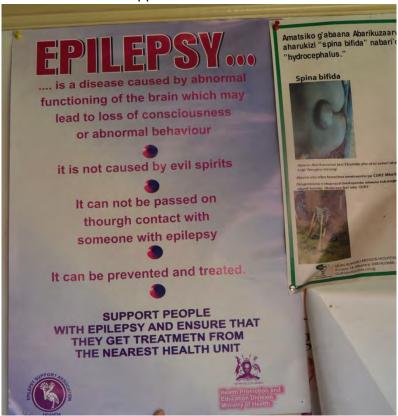


Image 12: Awareness raising advertising combatting stigma related to epilepsy

Finally, knowledge about common conditions like asthma and epilepsy, as well as a range of other illnesses and disabilities, appeared limited. A Congolese participant, who had been sexually attacked during the conflict in DRC, was suffering significant trauma. This was attributed to black magic: "later they bewitched

her. She at times become mentally disturbed because of charms". Such explanations were common amongst conditions that were not properly understood.

This led not only to barriers in treating and avoiding the development of some conditions, but it also meant that persons with certain conditions faced high levels of discrimination and shame. One organisation we visited - Organised and Useful Rehabilitation Service (OURS), based in Mbarara city, had on display posters aimed at raising awareness about conditions which were commonly misunderstood.

11. Participation

11.1 Employment and income generation

11.1.1 Employment-related challenges

Many participants considered limited employment opportunities as a major barrier to basic needs like food, medical care and education. The inability to generate an income can also increase the vulnerability of individuals and their families, as this urban participant recognised:

"You give birth to children, you have to provide for them and you can't do any work. The children lack everything, they end up becoming street children" (Urban discussion group participant)

The general lack of employment options was reported by UNHCR staff as being a key cause of depression amongst many refugee men in Nakivale.⁷⁷

Many participants reported that they were unable to find suitable employment, given their context. In the settlements, most people rely on crop cultivation to serve as a supplement for WFP rations and also as a source of income. One participant noted: 'I have no job matching my disease.'

Participants shared their experiences of discrimination when seeking employment:

"He was discriminated due to take long to listen to other and was dismissed from the work because of the same problem." (Male, DRC)

"Sometimes I do apply for some jobs after being employed before completing my disability is ever revealed to them there and then so you find that everyone knows me and cannot employ me. " (Female, DRC)

"One day I was selected as a staff member at the reception and most of time I could not hear or do properly what I was requested and could not do as requested then he dismissed me." (Male, unspecified)

Refugees with disabilities who were not working also reported their unemployment or lack of income as a source of discrimination amongst their families and the community. This can contribute to depression or psychological distress.

"Being sick every (day), all people came to blame me for this condition that I am not useful to the community." (Female, Burundi)

"People often tell me that I am there only for eating and that I have no any advantage in community because I cannot do anything" (Male, Burundi)

"He feels unsafe. Many say bad things to him. He doesn't work so they hate him." (Male, Burundi)

Finally, employment and income generation can be a hazard for refugees living in desperate situations. As mentioned in the section on acquisition, work-related accidents can be a cause of disability. Persons living in vulnerable situations, including some of our participants with disabilities, can be forced into implementing dangerous survival strategies, such as prostitution for food (as participants reported) or take part in other forms of exploitative employment.⁷⁸ UNHCR also noted that refugees who sell cultivated crops were often

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⁷⁷ Interview, UNHCR Mbarara, 2 September 2013.

⁷⁸ Jeff Crisp, 'No Solutions in Sight: Protracted Refugee Situations in Africa', in Itaru Ohta and Yntiso D. Gebre (eds), *Displacement Risks in Africa: Refugees, Resettlers and Their Host Population*, 17, 36-7.

taken advantage of and did not receive the rates which would be expected by local vendors.⁷⁹

11.1.2 Overcoming employment-related challenges

As discussed earlier, short-term funding was used by UNHCR and its partners (in part) to assist refugees with disabilities to form groups and initiate income generating activities. Interviews with the Refugee Law Project and NUDIPU representative, Mr Martin Babu, drew to our attention the importance of assisting groups to maximise the outcomes of such projects. In this respect, it is important that funding given for income generation is accompanied by skills development and feasibility evaluations, to ensure that such investment is capable of fulfilling its intended aims and leads to long-term empowerment.

Access to employment opportunities is also linked to education and vocational training. Interaid Uganda mentioned successful cases of urban refugees who had been given access to skills training. From this experience, some had started their own businesses or gained employment. Some refugees with disabilities in Nakivale reported having access to similar livelihood-focused training. Refugee participants also recognised the importance of vocational skills, as well as suitable equipment and capital, to ensure successful ventures.



Image 13: Man in Nakivale works using a donated sewing machine

11.2 Education and vocational training

In Uganda, refugee children and youth have the right to attend government schools; however there are many challenges to access both for refugees with disabilities and refugees more generally. There are a number of primary schools in Oruchinga and Nakivale, and a single secondary school in each. While Uganda has a policy of universal primary and secondary education, there are many obstacles for children with disabilities.

Some students with disabilities attend specialised schools, while others attend mainstream schools, with

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⁷⁹ Interview, UNHCR Kampala, 26 August 2013.

varying levels of accommodation. Of the 114 school-aged questionnaire participants, 52 said that they attended school and 48 said they did not (a further 14 did not specify). Boys were more likely to attend than girls.

Table 14: School attendance of school-aged participants (5 to 17 years old), by gender

Gender	Attends	Doesn't attend	Unspecified	Total
Female	24	25	10	59
Male	28	23	4	55
Total	52	48	14	114

Education options for adults are more limited, although some participants mention attending English classes.

11.2.1 Barriers to education

School fees and associated costs were identified as a major barrier to education. Interaid Uganda note that there are nine 'special schools' in Kampala, but that while they have identified 71 urban refugee children with disabilities, only 26 have access to these schools, due to funding limitations. Specialised schools are particularly expensive. A major school, Kampala School for the Physically Handicapped, costs one million shillings per child. Given the isolation of the refugee settlements, children attending schools often board at the schools during school terms, creating an extra cost for parents. Poverty also prevents refugees from attending school when other commitments take priority, such as working or caring for family members.

"I always think of necessities [like] food, shelter, water, that is why I don't attend." (Male, 28, Somalia)

Distance can also be a barrier for children with disabilities: the location of the nearest bus or other form of transport (when these are accessible), may be at some distance from children's homes. In the vast settlements, there are no sealed roads and no footpaths, making travel difficult. One mother wrote of her experience carrying her son to school on her back.

Many explain how unaddressed assistance needs related to their impairments undermine their experience in class or discourage them from attending.

"When I was at school I couldn't write well. So I stopped because my arm was painful" (Female, 17, DRC)

"..it is difficult for me to walk and move" (Male, 14, Burundi)

"School doesn't cater for her disability and she can't afford all the school materials she needs" (Female, 14, Burundi)

"The difficulties is that he can't hear properly till you shout or speak loudly" (Male, 9, Somalia)

RLP research on this area resulted in similar findings. They found that a lack of accommodations, in terms of assistance, as well as the physical inaccessibility of buildings, created barriers for refugee children with disabilities. This is further exacerbated by the fact that most children board at school, meaning that these barriers are constant.⁸⁰

Discrimination is a problem faced not only by refugee children who have disabilities, but refugee children

⁸⁰ From the Frying Pan into the Fire: Psychosocial challenges faced by vulnerable refugee women and girls in Kampala (Refugee Law Project, April 2014), 19.

more generally. An Inspector of Schools, based in Mbarara, outlined events in local schools where there had been tension between local and refugee students which in one case led to the closure of a school. Language barriers are a problem and staff approaches to disciplining students can sometimes be questionable, including beating. While training is given, staff turnover means that there are always new teachers needing sensitisation.

Disability-related discrimination is also a concern. In some cases, people are discouraged from attending classes in order to avoid discrimination. For those who do attend it can be a damaging experience.

"I cannot play like others and always other students laugh at me and some time I cannot attend the school" (Male, 14, Burundi)

"I feel tired because of long distances or sometimes I bleed" (Female, 8, DRC, survivor of sexual violence)

"I would like to take language classes but I am ashamed of what happened to me" (Male, 32, Burundi, survivor of sexual violence)

"The schools are too far away and he cannot walk and too hard to move on hands for that distance. Also, he is beaten by other children" (Male, 7, Burundi)

Discrimination can also act as a barrier within the family. It has been observed that children with disabilities are more likely to be kept out of school than their siblings. Female children may also be disadvantaged in this regard.⁸¹

"We have heard about the school for the deaf, but we don't have enough money to send him. (Older brother attends secondary school, but sometimes has trouble with fees)" (Brother of Male, 6, Burundi)

11.2.2 Overcoming barriers to education

Much like with employment, education has been a priority area in the use of targeted funding to empower refugees with disabilities. As mentioned in the section 11.1.2, above, this has included vocational training for adult refugees with disabilities. Through funding provided by One Billion Strong, UNHCR identified and assisted 80 children with disabilities to access education, through the provision of scholarships, scholastic materials, uniforms and materials required for boarding (eg mattresses and soap).

As mentioned previously, the Kambara project, run by the Mbarara branch of the Ugandan National Association of the Deaf and funded by Action Aid Uganda, operates a school in Isingiro district, close to the border of Oruchinga refugee settlement. We met two refugee children in Nakivale who attend this school and who were able to sign their names.

Finally, we identified facilities that have the potential to allow greater accessibility to learning for refugees with disabilities. This included a large computer lab, located in Nakivale, which was funded by Australia for UNHCR. Our visit to a school in Mbarara - which includes an annexe for students who are blind - also had a similar, albeit smaller, computer lab. Computers can become accessible to persons with vision impairments through the use of screen-reading software. At the school – St Helen's – we offered to share a free version of such software with the IT staff, who had not heard of it before. Similar software could be installed on the computers in Nakivale.

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 $^{^{\}rm 81}$ Interview with Inspector of Schools, Mbarara, 2 September 2013.

11.3 Community and family inclusion

11.3.1 Barriers to participation in community and family

Along with the physical and environmental barriers to participation which have been outlined in the preceding sections, discrimination and stigma were common problems faced by refugees with disabilities. Even where other barriers are overcome, the social barrier of discrimination can present a large obstacle to equal participation in the community and family for persons with disabilities. Particular areas of concern identified during our research include misunderstandings about the nature of certain diseases and their causes, as well the ostracism of survivors of sexual violence.

"When men know that I have been raped, they don't respect me. They said in the village that my children don't know their father" (Female, 22, DRC)

"People in the village are scared of him, especially when he falls, everyone runs away and they don't want to stay near him" (Male, 38, DRC – with epilepsy)

"Neighbours do not wish even to see me. They think I can spread my disability to them and their children so they do not want me to be around. I spend my time inside" (Male, 22, Rwanda)

For many participants discrimination restricted social participation, as well as undermining their ability to undertake many daily activities, including those listed in preceding sections of this report.

"Others who are my age see me as if I am not their equal and they don't want to cooperate with me" (Female, 14,DRC)

"Because my problems that I got my husband hates me" (Female, 24, DRC)

"Both relatives and citizens discriminate me to the extent of fencing all land around me and other domestic violence" (Female, 40, Burundi)

"People see I don't work. My children are also discriminated against because they beg in the community" (Female, 48, DRC)

"E is my third child after two miscarriages. Her father deserted us because of her disability." (Mother of Female, 5, DRC)

It was a source of depression and undermined self-value and sense of identity. Below is just a short sample of the many experiences of discrimination shared by the research participants.

"Because of my sickness people laugh at me and I am shamed by the community" (Female, 20, DRC)

"I try to stay on good terms and be nice to those around me as I rely on others" (Male, 41, Rwanda)

"Many people discriminate me because of my disability and others laugh at me. So I feel shocked and anxious and unimportant" (Male, 21, DRC)

11.3.2 Overcoming barriers to participation

A number of existing initiatives aim at overcoming barriers to participation. By assisting persons with disabilities to access employment and sustainable income generation, these persons gain agency and independence. The creation of associations of persons with disabilities is also a positive step, as is the creation of groups of survivors of sexual violence and related activities. Finally, awareness raising and education about different types of disabilities and illnesses may go some way to overcoming the stigma currently attached to them. These types of initiatives must continue to receive support to ensure that the talents and strengths of refugees with disabilities are recognised and promoted.

12. Conclusion

This report has provided an overview of the situation for refugees with disabilities living in Kampala and in Nakivale and Oruchinga Refugee Settlements in south-western Uganda. It has outlined a number of barriers in terms of ensuring their rights. First, the identification of refugees with disabilities remains limited and requires reform. Second, despite initiatives to assist and empower refugees with disabilities, there are still many challenges in terms of the provision of material assistance, ensuring accommodation and access to facilities and combatting discrimination.

While the Government of Uganda, UNHCR and other organisations have taken promising positive steps to support refugees, including those with disabilities, there remains much work to be done to overcome the challenges outlined in this report. It is our hope that the Government of Uganda, UNHCR and its partners will continue to work with researchers, Disabled Persons Organisations and other interested parties to increase knowledge and understanding of the situation and experiences of refugees with disabilities; and continue to work towards ensuring that their rights are realised.



Image 14: Two refugee children sit outside a computer centre in Nakivale Refugee Settlement

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