IMPROVING COMMUNICATION WITH REFUGEES WITH COMMUNICATION DISABILITIES

A case study from north-west Tanzania

UNHCR
The UN Refugee Agency

Cover photo: Refugees read information on COVID-19 displayed at a distribution center in Nduta Refugee Camp, Tanzania.

Photo credit: UNHCR/Winnie Itaeli Kweka

Title: Improving communication with refugees with communication disabilities in north-west Tanzania.

Project objective: To explore augmentative and alternative tools to improve communication with persons with communication disabilities.

Dates: February 2019 - ongoing

Population groups: Refugees

**Partners:** HelpAge International, Community members.

⟩ PROJECT OVERVIEW

This initiative sought to work directly with persons with communication disabilities to identify and better understand their communication difficulties and the barriers they may face. Through this innovative approach, a set of pictograms and photographs to augment communication was designed, created and tested among Burundian refugees with communication disabilities, in their communities.

⟩ CONTEXT

The United Republic of Tanzania has had a long and generous history as a refugee hosting country. As at 31 May 2020, the country was hosting 283,890[1] refugees and asylum-seekers, mainly from Burundi and the Democratic Republic of the Congo, the majority of whom reside in three camps in Tanzania. Due to the protracted refugee situation in Tanzania, refugees and asylum seekers remain highly dependent on humanitarian assistance. Chronic underfunding has resulted in serious gaps across various sectors, leaving many persons of concern exposed to numerous protection risks. Given the continued insecurity in the east of the Democratic Republic of the Congo, prospects of voluntary repatriation of Congolese refugees remain minimal. UNHCR has assisted the voluntary return of some 85,220 Burundian refugees from Tanzania since 2017.[2]

During a participatory assessment in Nduta camp in 2018, various physical, attitudinal and communication barriers to accessing services and assistance were highlighted by persons with disabilities. Focus group discussions with persons with disabilities and their care providers indicated that they faced numerous challenges in accessing services and assistance inside the camp. Persons
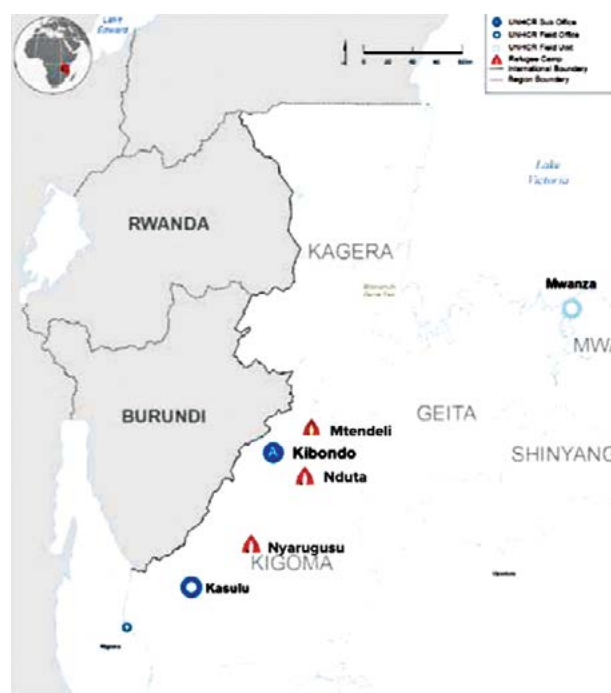
Map of North-East Tanzania indicating the location of the refugee camps and the UNHCR offices.

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[1] UNHCR Tanzania Refugee Population Update, 31 May 2020
[2] Ibid.

with disabilities remain at heightened risk of exposure to exploitation, violence and abuse and face multiple and compound forms of discrimination on the basis of disability and their refugee status.

Through anecdotal observations and discussions with refugees with communication disabilities, their carers and service providers, it became evident that many depended on the support of a trusted carer to communicate their needs, wants and desires and to facilitate access to services. In particular, persons with speech, hearing and intellectual disabilities struggled to communicate directly with service providers and other community members. As a result of this communication barrier, many of their needs were left unmet. Although sign language training and interpreting services were available inside the camp, not all persons with communication disabilities knew or used sign language, thus indicating a need for other communication support strategies.

Augmentative and alternative communication (AAC)

Persons with communication disabilities have difficulty using speech to express themselves and/or understand what others communicate to them.

Augmentative and alternative communication (AAC) encompasses a range of tools and strategies to help persons with communication disabilities to understand what is being said to them and/or help them express what they want to say. AAC may be 'unaided', i.e. not requiring assistive devices (relying instead on gestures, facial expressions and sign language, etc.), or 'aided' (may include the use of objects, photographs, line drawings, printed text _and electronic speech-generating devices, etc.).[3]

PROJECT BACKGROUND

In January 2019, UNHCR collaborated with HelpAge International to explore how communication with persons with communication disabilities might be improved in Nduta camp. To do this, a human-centred design approach was employed to better understand the types of difficulties and barriers that persons with communication disabilities face. This approach was selected, because it involved persons with communication disabilities as end users and encouraged them to bring their expertise and resources to the project. This was crucial to the iterative processes of designing, building, and testing strategies and tools to augment communication. HelpAge International also managed a community centre in Nduta camp that provided specialized services targeting older

persons and persons with disabilities. This space served as an ideal location from which to launch the project, as it was a familiar space that persons with communication disabilities felt comfortable accessing. The specific objectives of the project were:

❯ To identify and better understand the communication challenges and barriers faced by persons with communication disabilities.

❯ To design, build and test tools and strategies to improve communication with persons with communication disabilities.

PROCESS AND ACTIVITIES

By positioning persons with communication disabilities as active participants, the focus on their 'vulnerabilities' and 'specific needs' shifted and instead sought to empower them as agents of change. As a result, humanitarians were able to learn from refugees, who participated in the problem-solving process. This was essential to designing successful, sustainable solutions.

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[3] Department of Human Services, Government of South Australia https://www.sa.gov.au/__data/assets/pdf_file/0013/17122/augmentative-alternative-communication-.pdf

Photo credit: Judith Chan, UNHCR

HelpAge staff show participants how to use the camera.

UNDERSTANDING THE NEEDS OF PERSONS WITH COMMUNICATION DISABILITIES:

Several group and individual discussions were held with six Burundian adults and two children with communication disabilities, as well as their carers and two Burundian refugee sign language teachers in HelpAge International's community center in Nduta camp. Through these informal discussions, UNHCR and HelpAge International staff gained more insight into the communication barriers participants faced in their daily lives. Participants – who self-identified as having hearing, speech and intellectual disabilities and used various communication methods, including French, Kirundi, Kiswahili, American and pidgin sign language and, in some cases, written communication and support from their carers – shared their experiences of being misunderstood and wrongly identified as having a mental illness, because their communication needs were often invisible to others. Stigmatization by community members, exclusion from social activities and breakdown in communication whenever participants approached service providers inside the camp were also identified as frustrating and unpleasant daily experiences

Several participants indicated that although they were learning sign language they could not use this skill to communicate with their families, neighbours and service providers without an interpreter.

Following these discussions, participants were invited to form a small group where they could explore potential strategies for addressing communication challenges. A group of six adults, two children and their carers indicated their interest in testing various solutions to improve communication together with UNHCR and HelpAge International staff and refugee sign language teachers.

Photo credit: Judith Chan, UNHCR

Testing the photographs and pictograms in the market in Nduta Camp.

EXPLORING AUGMENTATIVE AND ALTERNATIVE COMMUNICATION:

Among aided augmentative and alternative communication (AAC) strategies, pictograms (also known as symbol sets) were selected as a starting point because of their low cost and accessibility through free resources on the internet. Over the course of a month, the group was introduced to a series of symbols comprising black and white line drawings. This was the first time participants had worked with pictograms and each took turns to sift through the pictograms and pair them with signs, gestures and, where possible, the real object that they represented.

To select the best pictograms for use as tools to augment communication, the group organized the pictograms into two piles: 'good' ones, which were easily understood and 'bad' ones, whose meanings were unclear or ambiguous. Through this exercise, the group identified some pictograms as being too abstract to be understood, having multiple meanings for different people or too much or too little detail. On this basis, it became clear that the symbols needed to be specific to the local cultural context, because the more closely they represented a real, known object, the more sense they made.

In search of a more context-specific tool, photographs were also explored by the group as another potential strategy to support communication. Using a handheld digital camera, the group took pictures of objects, people and locations in the community centre. For many, this was their first time using a camera. The group then took the printed photographs and walked around the centre again, pairing them with the actual objects, people and locations and confirming the correct referent. Building on this, group members visited the market inside the camp, where they took various photographs. This process piqued the interest of community members and market traders. After amassing a collection of photographs, the group began sorting them into booklets according to camp locations.
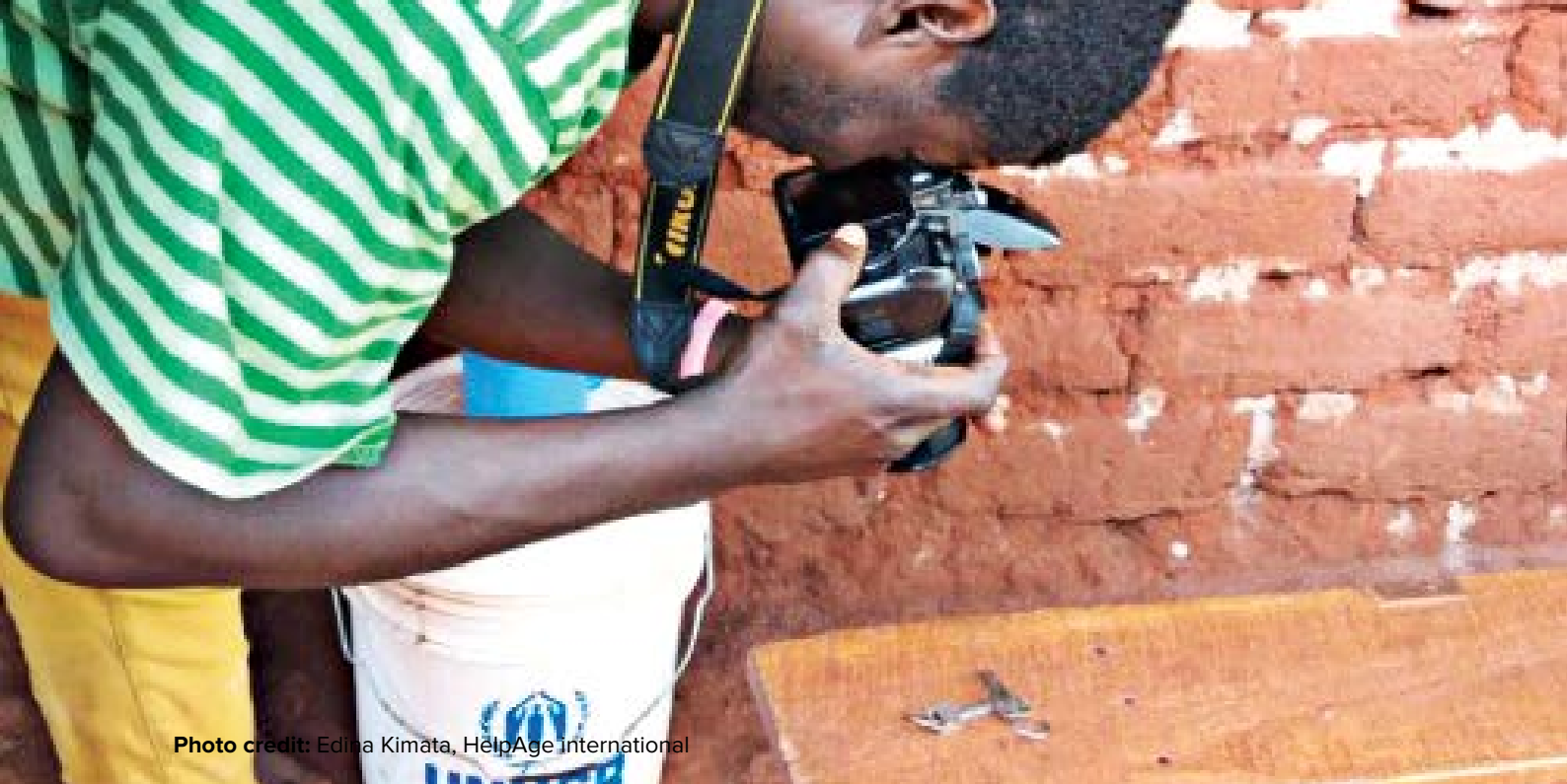
Photo credit: Edina Kimata, HelpAge International

Taking photos of common everyday objects in Nduta camp.

TESTING THE TOOLS:

After organizing the photographs, the group returned to the market to test how the photographs and pictograms could be used. Through this process, it was discovered that simply pointing to various photographs to convey a message was not understood by most community members. Although most community members were interested in seeing the photographs, they did not seem to understand what group members were trying to do with them. Following this, the group then decided to take 'better' quality photographs and include the written word the photograph represented at the bottom in Kirundi and Kiswahili. The group tested the tools again and discovered that they were more successful in having their messages understood by community members when they paired the photographs with pictograms and various combinations of hand and body gestures and facial expressions. Since it was equally important that group members understand the messages of community members, the latter were also encouraged to use the photographs and pictograms as well as gestures and facial expressions to convey their message during this test process, in order to facilitate two-way communication.

To address communication challenges at home, group members decided that they wanted to build and test a collection of photographs of important vocabulary that they needed to use in their everyday lives, including common household items, family members, friends, and locations in their homes. The participants then invited each other into their homes to take photographs and to meet their family members.

Staff who had experience of living with a communication disability and who possessed knowledge and experience of working with AAC and persons with communication disabilities were an enabling factor. This expertise provided technical guidance to participants and helped to build trust.

Taking time at the end of each session to debrief gave participants the opportunity to provide feedback on the exercise. Group members indicated their pride in being part of the project and their desire to continue tailoring the tools for potential use in the camp's hospital, at the police station and at other service points. This time was also critical to identifying successes and failures, thereby informing the iterative process and ensuring accountability.

Teaching group members how to take photographs meant that they were able to select and photograph objects that were significant to them. This also

helped to ensure greater ownership and sustainability of the process, because it harnessed the capacity to produce and reproduce the photographs. Collaboration with a professional photographer during a later test stage could also be useful to improve the quality of the photographs.

Persons with communication disabilities are often under-identified. Achieving gender balance in the group was a challenge as there was only one female participant.

Involving sign language teachers in the process not only supports communication, it also adds valuable teaching skills to the exploration process.

There is no best way to use pictograms and photographs to support communication. What works for one person may not work for another and effective use of the tools depends on individual abilities, needs and personal preferences.

NEXT STEPS

◉ Expand partnership and collaboration: having identified technical sectors and service providers in Nduta camp, HelpAge International shared a sample collection of photographs to introduce the project, which was received with strong interest. HelpAge International and UNHCR are exploring opportunities to expand the project and strengthen communication accessibility and disability-inclusive programming.

◉ Refine the tools: group members identified the police station, community centre and market inside Nduta camp as priority locations at which the tools were needed. HelpAge International intends to print the photographs with texts in Kirundi, Kiswahili and French and to design a booklet with the participants that will be disseminated to key actors. The tools will then be incorporated into communication accessibility training for protection actors, including police, for further testing.

ANNEX 1

DISTINCTION TABLE

Below you will find the categorization table for field practices. The practice above from Tanzania has been defined as a case study based on the criteria below:

	Case Study	Emerging Practice	Promising Practice
Rationale	Capture practices to provide information on process, insights and lessons that are of interest (topics, themes etc.), but there is no requirement to evidence the study. The purpose of case studies is to capture successful and/or unsuccessful attempts to implement a project. These are considered valuable for learning and improving. There is a requirement that the study was designed to meet minimum criteria in <u>design.</u>	Identify and track practices which may have not yet produced sufficient results but there are indications that it could. The practice should not have been documented elsewhere with an exception of programme evaluations. There is a requirement to ensure that it meets the minimum criteria in <u>design and results.</u>	Document and share practices that are promising. The practice should not have been documented elsewhere with an exception of programme evaluations. There is a requirement to ensure that it meets the minimum criteria in <u>design and results.</u>
Definition	Descriptive and explanatory overview of a practice, or part of a practice, without requirement for provision of evidence or any judgement as to its value or sustainability. It can provide insights and lessons learned into future programming.	Practice that shows early indications of producing positive results to transform lives of individuals or communities.	Practice that is proven to work well and produce sustainable results, and has a protective and/or transformative potential for individuals or communities, as demonstrated by quality and reliable evidence. It can serve as a model to be replicated and scaled up.
Results (evidence level)	**No results are required.** It is a plain explanation of the process that does not have any results or may have very limited results such as quotes about the process.	The availability of indications can be **'showing signs of some aspects' to 'consider producing positive results along the way'.** Indications can be assessment (qualitative or quantitative) or monitoring results that do not have a comparison with a baseline. An emerging practice should be something that has the potential to become a promising practice	There should be some **existing results** of effectiveness of the practice demonstrated as positive changes that the practice is making. Baseline and midline or endline data (qualitative or quantitive) should be available as well as documented results before and after the practice is carried out. When results are not documented, the practice can be still considered if staff members or partners can provide a detailed account on observable changes.

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[1]A demonstration of attempted adherence refers to those practices that attempted to apply the criteria and did not succeed for various reasons such as context/operational environment etc. It is recognised that all practice implementation must strive toward adhering to and achieving the criteria. It is acknowledged that there are lessons to be learned from challenges faced and unsuccessful attempts.

	Case Study	Emerging Practice	Promising Practice
Inclusion	Can be a study that is inclusive of all groups or that is targeted.	Can be a practice that is inclusive of all groups or that is targeted.	Can be a practice that is inclusive of all groups or that is targeted.
Criteria *optional ®Should only be indication that these were considered in the design phase in order to allow for capturing all types of case studies.	Relevance® Participation® Age® Gender® Diversity® Do no harm® Innovation*	Relevance Participation Age Gender Diversity Do no harm Innovation* Results (indicated outputs/outcomes/impacts)	Relevance Participation Age Gender Diversity Do no harm Innovation* Results (outputs/outcomes/impacts) Sustainability Replicability Scalability
Timeline	No minimum requirement for implementation duration. Can be on-going or recently completed.	No minimum requirement for implementation duration. Should be on-going.	Implemented within the past 3 years, can be concluded or ongoing.
Submission	All submissions, regardless of a category, will be submitted using a common template to describe the practice briefly (not more than three pages) applying a self-rating tool		
Process ***clearance is only needed for documents for external publication**	Self-rating by the field operation Review by HQ to confirm self-rating Completion of documentation by field team Review of documentation by HQ + editing Publish on intranet	Self-rating by the field operation Review by HQ to confirm self-rating Completion of documentation by field team Review of documentation by HQ + editing Approval and clearance (for external publications) at field level (+Bureau) Clearance at HQ and publish	Self-rating by the field operation Review by HQ to confirm self-rating Completion of documentation by field team Review of documentation by HQ + editing Approval and clearance (for external publications) at field level (+Bureau) Clearance at HQ and publish
How it will be used	Can be hosted online (intranet) Incorporated into learning tools and materials Can be offered as examples in various reports	Can be hosted online (intranet) Can be published in print or online for external audiences Incorporated into learning tools and materials Can be offered as examples in various reports	Can be hosted online (intranet) Can be published in print or online for external audiences Incorporated into learning tools and materials Can be offered as examples in various reports