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Care relations under pressure:

Displaced South Sudanese with chronic disabling conditions in times of humanitarian funding cuts

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ADAPT: Adapting Humanitarian Response to Refugees' Endeavours:
Managing Food and Health Insecurity

Woman in her home in a Kenyan refugee settlement @ Ayo Degett/DRC

The 2025 report on preliminary findings

This report presents the preliminary findings of Adapting Humanitarian Response to Refugees' Endeavours: Managing Food and Health Insecurity (ADAPT) during the project's first year of implementation, 2025, in Uganda, Kenya, and South Sudan. The project is generously funded by Novo Nordisk Foundation (NNF). The report has been written by Ayo Degett (PhD), Programme Manager (Research), Pernille Sikker Hansen, Project Officer, both with the Danish Refugee Council (DRC), and Susan Reynolds Whyte, Professor at the Department of Anthropology, University of Copenhagen (UCPH), with support from Mette Lind Kusk (PhD). The contents and opinions expressed in this report represent the authors' views and should not be attributed to, and do not necessarily represent, the views of NNF.

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Child walking into the market in a Ugandan refugee settlement @ Ayo Degett/DRC

Executive Summary

Adapting Humanitarian Response to Refugees' Endeavours: Managing Food and Health Insecurity (ADAPT) is a peer-driven anthropological research project implemented by Danish Refugee Council (DRC) in partnership with the University of Copenhagen (UCPH) and funded by Novo Nordisk Foundation (NNF) 2025 – 2026. The project is carried out by DRC's longitudinal research initiative, the Participatory Research Team on Community-Led Action (PARTOCA). The project explores the coping practices and care of South Sudanese refugees living with chronic disabling conditions (loss of functioning that requires everyday care[1]) in refugee settlements and urban areas in Kenya and Uganda, and some who have returned from these areas to South Sudan. Simultaneously, the study follows community-based institutions and care providers, humanitarian actors, and formal health providers. ADAPT aims to contribute to advancing and improving care for refugees with chronic disabling conditions by investigating which community support structures persist and work to support people with these conditions, and by exploring how these community structures can be better supported, prioritised, and scaled up by humanitarian actors to adapt to current circumstances. ADAPT works with peer researchers, refugees trained in ethnographic methods, who follow households affected by chronic disabling conditions in their own communities.

In this report, we present preliminary insights from the first year of the project, documenting refugee efforts to care for chronic disabling conditions as humanitarian aid rapidly shrinks. With the understanding that care is always a social relationship, we examine three general – and overlapping – kinds of care relationships and their interconnections: familial, sociable, and institutional care relations. The study focuses on chronic disabling conditions that require daily care from others. The daily responsibilities for bodily, social, and emotional care are often taken on by relatives or, in some cases, by household members or neighbours who are available to assist regularly. Familial care relations are thus often kinship-like and imply close familiarity, intimacy, and proximity. Sociable care relations are based on the sociality of the community, and sociable care is provided by fellow community members who recognise a need and respond – often ad hoc. Finally, institutional care relations are professional, supported by some resources, and formal in that they are recognised by political authorities as relations whose primary purpose is to provide a service of care.

The cutbacks to resources for institutional care, particularly food assistance, and the shrinking of resources for healthcare, affect households with chronic disabling conditions disproportionately. In this situation, people are becoming more dependent on familial and sociable care relations. While familial relations are adjusting as best they can to current conditions, there are limits to the livelihood activities these vulnerable households can undertake. Sometimes, the best option is to relocate – to look for livelihood, support from relatives, or better medical care – despite the challenges increased mobility can present for these households with chronic disabling conditions.

Although sociable relations of care are less regular than familial care, they continue to be important, and ad hoc interventions of support offered for households and individuals affected by chronic disabling conditions in a dire situation can compensate for their vulnerability and help them survive.

Through a deeper understanding of how care relations unfold and are practised in this extended hardship, perspectives for improving conditions for care are brought forward. This report lays the groundwork for the next paper, which will focus more on concrete recommendations and opportunities, based on the full study period.

1 We define chronic disabling conditions in line with WHO's International Classification of Functioning, Disability and Health (ICF).

Man with a leg impairment repairing shoes in a Ugandan refugee settlement @ Ayo Degett/DRC

1. Introduction

This report forms part of the research project, Adapting Humanitarian Response to Refugees' Endeavours: Managing Food and Health Insecurity (ADAPT), implemented by the Danish Refugee Council (DRC) in partnership with the University of Copenhagen (UCPH) and funded by Novo Nordisk Foundation (NNF). The project is carried out by DRC's longitudinal research initiative, the Participatory Research Team on Community-Led Action (PARTOCA), drawing on its data, research findings, and network from the same research locations over the past eight years.

Refugees living with chronic conditions and disabilities in camps in Kenya and Uganda have been severely affected by the sharp decline in humanitarian funding, worsening during 2025. Their disabling conditions and impairments require extra support, and for that, they are dependent on social relations of care. In this report, we discuss three types of care relationships: familial (most often provided by intimate others like close relatives and neighbours); sociable (most often provided ad hoc by local actors but also by community groups); and institutional (provided by health facilities, some Non-governmental Organisations (NGOs), and local governance structures). As we will show, the nature of care in any of these relationships depends on aspects such as the type of chronic disabling condition, social connections, geographic location, and access to resources.

Funding cuts have reduced access to medical treatment, food assistance, protection activities, security actors, shelter, livelihoods programmes, and other core services provided by humanitarian actors. People living with severe health conditions are particularly vulnerable to the cutbacks in services, as they are less capable, physically and/or mentally, to cater for their own needs and engage in income-generating activities for food, medical care, and survival. With these funding cuts, the medical, economic, physical, and social care for these people has rapidly been put under extreme pressure. As a result, local support structures are increasingly crucial for their ability to survive and lead dignified lives. There is no indication that humanitarian funding will be restored significantly, and it is therefore important that these local care structures remain in place and are supported as much as possible within the existing landscape of opportunities. Yet, we have limited detailed knowledge of how these structures provide care under current pressures.

ADAPT is a peer-driven anthropological study exploring the coping practices and care of South Sudanese living with chronic disabling conditions who have been forcibly displaced. The study takes place in two large refugee settings in western Kenya and northern Uganda, in urban areas, and among some who have returned from these areas to South Sudan. The current funding cuts mean that some South Sudanese living with health conditions and their families are moving between these settings for treatment or care. The study captures these movements and engages with the same households as they move between destinations. In parallel, the study is following community-based institutions and care providers, humanitarian actors, and formal health providers.

The overall aim of ADAPT is to contribute to advancing and improving care for refugees with chronic disabling conditions. It does so by providing in-depth knowledge of community-based care provision to help shape policy and programming for the new world order, where people in these contexts have very limited support from the international donor community. This report is the first of two in the study. It will provide preliminary insights and lay the groundwork for the analysis in the next report, which will focus more on concrete opportunities for improvement based on the full study period.

This report draws on data from Uganda, Kenya, and South Sudan. While we recognise important differences in conditions for care across these settings, we focus on general, widely relevant patterns. We ask:

1. Which types of community support structures persist and work to support people with chronic disabling conditions?
2. How can these community structures be better supported, prioritised, and scaled up by humanitarian actors to adapt to the current circumstances and enhance support for the chronically disabled across camp settings?

1.1. Chronic disabling conditions

In the ADAPT project, the study object is the care provided, with the goal of strengthening care relations under the current funding constraints. We focus on chronic disabling conditions that require daily care from others.

Accordingly, people who are well functioning, despite chronic conditions such as Human Immunodeficiency Virus (HIV) and diabetes, who have good access to treatment and can take care of themselves, are less relevant for the study. The diagnosis itself is not the crucial determinant for inclusion in our study. Some of these health conditions were undiagnosed (such as disabling chronic pain). Some people had conditions that might not have been disabling if they had access to treatment (such as endometriosis, depression, cancer, or sleeping sickness). It is the loss of functioning that requires everyday care. Amalgamating what might be seen as disability (sensory, motor, intellectual impairment) with chronic illness (diabetes, hypertension) is in line with the WHO's ICF. That emphasizes the importance of competence impairment, rather than cause and diagnosis, in considering health. Advanced arthritis in old age, cardiac dysfunction, traumatic limb loss, and diabetic foot can all impair mobility. We follow the ICF approach, adding that control or management of the condition is the main challenge for affected individuals and their communities (Whyte 2012).

Chronic conditions are often multiple in that the person has more than one grave health problem; a common example is the co-morbidity of hypertension and diabetes. But conditions are also multiple in that they affect more than one person. Caregivers' functioning can be limited by the needs of the persons in their care. A mother with a severely affected child may be less able to provide for the household. Thus, both the household and the child have a chronic condition. As some of the examples below show, food insecurity is exacerbated by disabling conditions.

The section below on data provides a more detailed overview of the chronic health conditions captured to date.

Newly arrived family in informal settlment in Juba, South Sudan @Ayo Degett/DRC

1.2. Care relations

Care may be bodily (feeding, bathing), social (visiting, including), economic (monetary), medical (diagnosing, treating), political (rights, acknowledgement), or emotional (comforting, appreciating).

It often involves practical and bodily activities, but it also includes supportive activities that contribute to a person's general well-being, such as social visits, attendance at funerals, or giving advice, as well as activities that manifest materially, such as giving gifts, money, or other forms of material support. In short, care actions express support or concern (Schuler 2024, 88). But no matter what its nature, care is always relational. So, we begin by characterising the kinds of relations in which it is provided. For simplicity, we have divided care relations into three types: familial, sociable, and institutional.

The most important care relationships are those within families and households, which could also be called 'primary' (Lynch 2022, 4). Very often, these are kinship relations, but non-kin may also take on the daily responsibilities of bodily, social, and emotional care. Typically, these are relations of proximity; the caregiver lives in the same house, or very close by, and is at hand to assist regularly with activities of daily living. The relationship is not only one of care. The caregiver is also a mother, sister, daughter, wife, neighbour. Care is one part of a multi-stranded relationship that has other dimensions too. We call these **familial** relations, with the understanding that they may be kinship-like and that they imply close familiarity, intimacy, and proximity.

The second kind of care relationship is based on the sociality of the community; we call it **sociable** because it arises from the condition of living together as social persons. Sociable care is provided by community members who recognise a need and respond. It is often ad hoc, depending on the situation and the ability of the sociable person to help in a particular instance. Often, the sociable person knows the individual or family in need, but this is not invariably so. Sometimes a 'Good Samaritan' gives a hand to a relative stranger. In the examples to follow, we see motorcycle taxi riders offering free transport and fellow church members taking up a collection. These relationships are not formal in that the care providers are not designated for the task of care, such as health workers or some NGO staff. Neither are they enduring and intimate as are those between members of the same household.

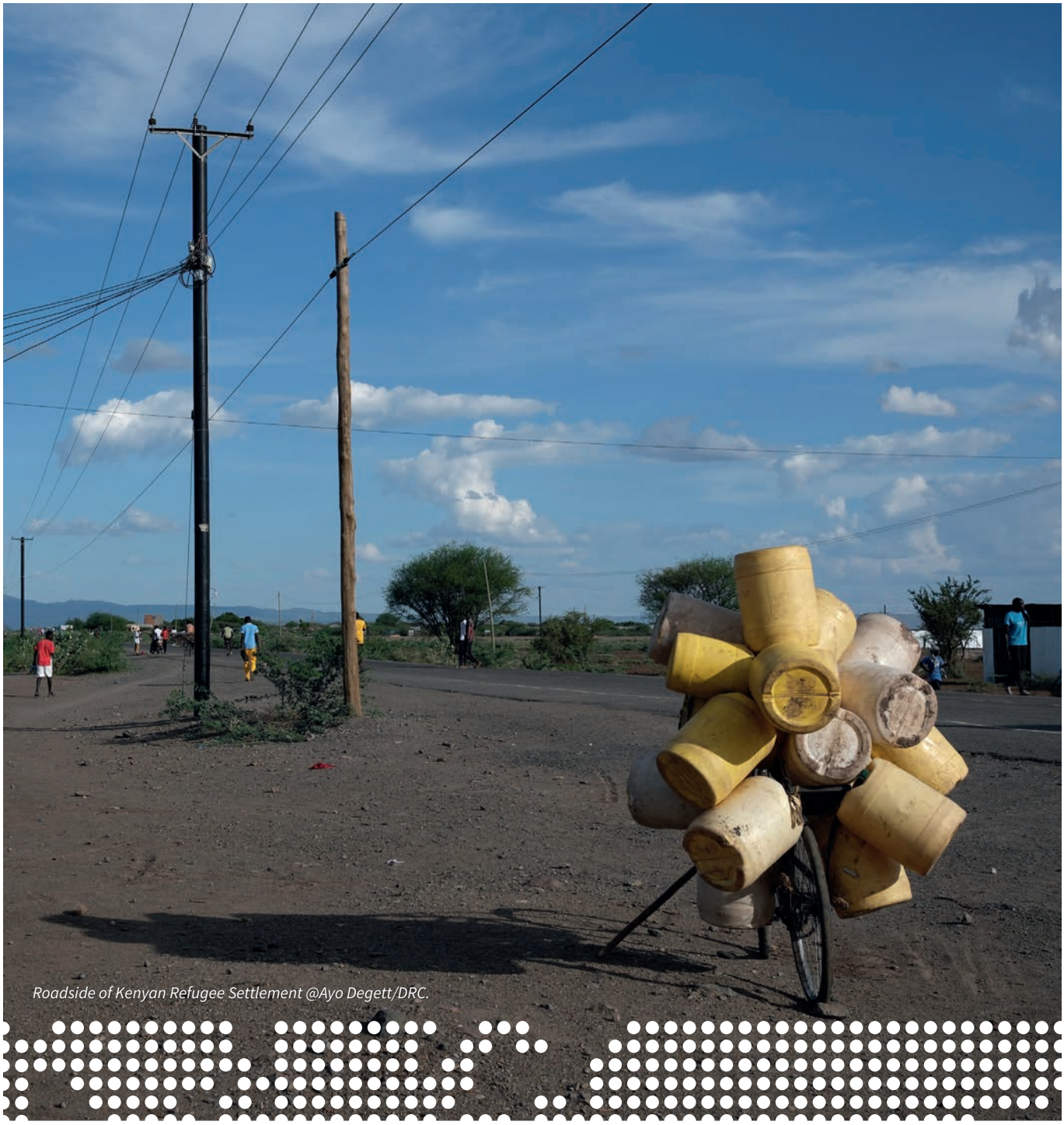
A third category of care relations is **institutional.** These are formal in that they are recognised by political authorities as relations whose primary purpose is to provide a service of care. Relations with health facilities and actors that support care facilitation, such as Village Health Teams (VHTs), some NGOs, the World Food Programme (WFP), and, to some extent, Refugee Welfare Councils (RWCs) and Community Health Promoters (CHPs), are examples of institutional care. They are more professional; the providers have some training and guidelines for their tasks of care, and they are backed by some resources for undertaking their work.

These three categories overlap; groups that sometimes provide care may be more or less formalised so that it is difficult to distinguish sociable from institutional relations. A household may have a sister working in a health unit or a son employed by an NGO. But what is important is not classifying relations so much as recognizing the links across types of care relationships. A relative working in Juba may send money so that a cousin in Rhino Camp can travel to Arua for expert medical care. A Village Health Worker may take a woman with a chronic disabling condition into her household, as in the case of Lucy and Kate described below.

In refugee settings, as elsewhere, care relations are strongly gendered. Familial care is almost always provided by women; they feed and clean those who need it. Men play a somewhat greater role in sociable and institutional care. Male family members who are working elsewhere send ad hoc financial contributions, and men are more likely to have institutional positions from which they can offer care.

Expressions and exchanges of support and concern are important not just for physical survival but also for social existence. Across various settings

in Africa, the ability to care for others through material as well as immaterial gestures is closely connected to becoming recognised as a person in one's own right (Cole and Groes 2016). To engage in caring, affective relationships is an essential part of becoming a full social person (ibid.). Building on this view, we consider care relations as going beyond narrow, instrumentalist understandings of care as enabling a function. Rather, being helped and cared for are activities closely intertwined with social life and connectedness (Schuler 2024, 95–96).



Roadside of Kenyan Refugee Settlement @Ayo Degett/DRC.

1.3. Relevance and background

Community support structures are often rendered invisible or overlooked by humanitarian actors (Schuler 2024, 87), yet as illustrated in our findings, they are becoming increasingly important as institutional support declines.

The ADAPT project offers urgently important insights into this aspect of the humanitarian field by exploring the features, opportunities, scalability options, and challenges related to the structures that will take over many of the functions that were covered by humanitarian actors until recently. The severity of the funding cuts is devastating to the health sector and other sectors intertwined with it, such as protection and food security. As an example, as the year 2025 closes, we are looking into a new year in which only 6% of the required funding has been secured for Uganda's refugee health system, leaving nearly 2 million refugees without access to lifesaving health and nutrition services (IRC 2025).

With the onset of the armed hostilities in South Sudan in 2013 (and escalating in 2016), which displaced millions of people, families fled to Uganda and Kenya in search of immediate safety and also in the hope of gaining better access to education, healthcare, and livelihoods. The stark decline in the number of households receiving food assistance and the reductions in the amounts of food for those still eligible have redirected their attention toward immediate survival strategies (Degett et al. Forthcoming). The cuts have forced most households to make more short-sighted decisions, which involve several negative side effects: It decreases the space for providing extra support to neighbours and more vulnerable community members in dire need (such as those with chronic disabling conditions) and it has also increased the triggers of conflict as people resort to negative coping practices such as theft, forced child marriage, child labour and substance abuse (OCHA 2025; Degett et al. Forthcoming). Therefore, despite a strong sense of moral obligation, community members' ability to offer support to people suffering from chronic disabling conditions is currently under severe pressure, as most face moderate or severe food insecurity (WFP 2025a, 2025b). This is only expected to worsen over time (ibid.).

Peer researchers conducting field work in a Ugandan refugee settlement @ Ayo Degett/DRC

2. Research set-up

The ADAPT project draws on PARTOCA's existing research infrastructure. This includes long-term engagement with actors and communities, with whom the team has built trust over the years, allowing them to be more open about their situations, challenges, and concerns. The project employs an overall participatory approach, which is meant to provide more ownership and decision-making power to the people who are the centre of the study, attempting to counter the research and assessments that are defined by people who are external to the context.

Our participatory approach is threefold: First, we co-design the study with the peer researchers of PARTOCA, who are residents of the refugee camps the study concerns. Secondly, we apply a refugee-led research modality, in which refugees collect ethnographic data, largely of their own choosing, in their own communities. The peer researchers follow people and households they believe present relevant perspectives to the discussion of care among families affected by chronic disabling conditions. Thirdly, the findings are presented and discussed with a refugee reference group on a bi-annual basis to verify the data, learn how they perceive our analysis, nuance it, and ensure accountability. The members of the refugee reference group represent people with disabilities, people with diabetes, caregivers, and health workers.

In addition to the refugee reference group, the yearly reports are discussed with an advisory group of leading academic experts in chronic disabling conditions, refugees, and global health[2].

2.1. Methodology

The data presented in this report builds on qualitative ethnographic methods, particularly participant observation and recurrent interviews with the same households, organisations, and local institutions throughout the duration of the study.

While the two lead anthropologically trained researchers, Pernille Sikker Hansen and Ayo Degett, conduct ethnographic fieldwork and interviews with families and stakeholders in Uganda, Kenya, and South Sudan every quarter, the PARTOCA peer researchers collect most of the data. Through their long-term engagement with local actors and families in the areas of the refugee camps where they themselves live, they identify a number of households and initiatives relevant to the research topic that they engage with on a weekly basis.

The team employs what is commonly referred to in anthropology as 'extended case method' (Burawoy 1998): It could be a specific problem, idea, or circumstance that unfolds for the person or initiative in focus, over time. An example is a peer researcher who followed a certain family for a full year in their search for treatment of the elderly mother, who was living with chronic pain. The peer researcher visited this family weekly, documenting their decision to move from Rhino Camp in Uganda to Juba in South Sudan, which offered better income opportunities but more expensive health treatment and less ideal conditions for the oldest son living with Down syndrome. The peer researcher documented the decision-making by paternal family members in South Sudan, their life and challenges in the new environment in Juba, the decision to move back to Uganda in July 2025, and

2 The academic advisory group includes Prof. Morten Skovdal, Prof. Wietse Tol, Prof. Tine Gammeltoft, Prof. Ayo Wahlberg and Prof. Susan Whyte.

the internal conflicts this decision sparked resulting in the second return to Juba by the end of 2025, where the family was interviewed as they were settling in for the third time in one year.

Focusing on extended cases is one of the primary strengths of the research setup: the local research assistants live in the communities studied, they speak the languages, have a deep understanding of the context, and are able to follow developments closely over time, exploring situations and interactions as they unfold day by day. Consistently following the same households and community initiatives over two years makes it possible for explanations, patterns, and nuances to emerge that are rarely observable in short-term interactions, survey data, or interviews alone. The research assistants receive weekly supervision on methodology and ethnographic writing to address any questions and agree on a way forward. At six-month intervals, they participate in comprehensive training in anthropological methods, ethics in data collection, and writing. The multi-sited aspect of the research setup provides a uniquely relevant fit for the group in focus. As the reader will learn in the following chapter, for families affected by chronic disabling conditions, mobility is an important aspect of life under the current funding cuts, and the multi-sited research focus allows the study to adapt to their movements.

2.2. Data

The data collected on ADAPT concerns individuals affected by chronic disabling conditions and their primary caregivers and family and the initiatives and groups that provide care for them.

In 2025, 44 recorded Key Informants Interviews (KIIs) were conducted: 19 in Uganda (16 camp-based and 3 urban), 15 in Kenya (13 camp-based and 2 urban), and 10 in South Sudan (all in urban settlements). These spread across households affected by chronic disabling conditions, community initiatives, camp governance structures, refugee leaders, and health care organisations and providers.

The research team follows 37 households affected by chronic disabling conditions. In some of these households, more than one member has such a condition, and because the team is also exploring the roles and conditions for the caregivers and breadwinners, the team often engages with multiple members within each household. In 2025, the PARTOCA research team engaged with a total of 99 households in the ADAPT research locations (37 of which were engaged specifically for ADAPT). Findings from data and insights from the engagement with all 99 households have provided important comparisons, background knowledge and depth to the findings presented in this specific report.

Because of the participatory approach described above, the peer researchers largely decided for themselves which households affected by chronic disabling conditions to include in the study. These presented a wide variety of conditions, household compositions, and ethnic groups. At an overall level, the conditions represented in the study can be categorised into two wide and overlapping types of conditions, noting that some individuals are affected by more than one:

- **Mental health conditions:** include cases of epilepsy, Post Traumatic Stress Disorder (PTSD), bipolar disorder, dementia, aggressive behaviour, depression, and unspecified mental health disorder.
- **Chronic disabling physical conditions:** include cases of paralysis, cerebral palsy (CP), walking impairment, blindness, deafness, Down syndrome, autism, unspecified developmental disability, diabetes, hypertension, heart disease, HIV, Acquired Immune Deficiency Syndrome (AIDS), chronic pain, and endometriosis.

In the affected households, chronic disabling conditions also intersect with other circumstances, such as being elderly and frail or having many dependents. Two additional factors are important. Most of the affected households experience extreme food insecurity, and although the study does not

include medical measurements for malnutrition, it is clear that some households in the study are also affected by malnutrition, which is the case for many households in the research location currently (OCHA 2025). In some of the households, there are members suffering from substance abuse. It is relevant as a factor negatively impacting affected households' ability to cope. We have selected these households because they often require community support, including assistance with care and access to resources.

Figure 1:

Occurrence of chronic disabling conditions per household

Forty community initiatives have been mapped for the study in 2025, of which 4 are NGOs and International Non-governmental Organisations (INGOs), and 36 Refugee Led Organisations (RLOs), community groups, and Community Based Organisations (CBOs). The research team focuses on community-led initiatives that conduct activities with the aim of supporting and improving resource access for households affected by chronic disabling conditions, such as strengthening their food security and climate adaptation, and also initiatives that more directly support the protection, dignity, and care of community members affected by illness, chronic disabling conditions, or social marginalisation. We have also engaged with health care organisations and providers in Kakuma, Kalobeyei, and Rhino Camp.

Woman preparing hot meals for new arrivals in Juba @ Ayo Degett/DRC

3. Conditions for care

In this section, we first outline some of the conditions for care experienced by residents in the research locations of the study: Uganda, Kenya, and South Sudan. Afterwards, we describe the support and opportunities available for affected households and members with chronic disabling conditions: the 'Persons with Specific Needs' (PSNs) categorisation, the food assistance, income-generation opportunities, and the coping practices employed.

3.1. Research locations

3.1.1. Uganda

The research in Uganda is conducted among South Sudanese refugees in Rhino Camp Refugee Settlement and in the nearest town, Arua, located about two and a half hours from the closest point of the settlement. The settlement, which has hosted refugees since 1980, is located on clan-owned land[3] and it stretches about 85km in rocky or swampy areas, which makes farming challenging (Degett 2023; Degett and Whyte 2023). As of the end of November 2025, 200,476 refugees and asylum-seekers live in Rhino Camp, of whom 93.06 % (186,567) are South Sudanese; others are from the Democratic Republic of the Congo (DR Congo), Sudan, and Rwanda, and a few from Burundi and Eritrea (UNHCR and OPM 2025). South Sudanese are granted refugee status on a prima facie basis in Uganda, which means they are provided asylum on arrival based on their nationality (UNHCR 2011, 103).

Multiple ethnic groups from South Sudan inhabit Rhino Camp, and because the settlement receives new arrivals daily, their composition changes. The households in the study include people from various areas of South Sudan, though mostly Nuer and Bari speakers, who represent the two majority groups in the settlement. Several households are located in Ocea, a central area of the settlement that tends to attract individuals and families who need to live in close proximity to health and transport facilities, such as those affected by chronic disabling conditions. Ocea hosts some of the largest health facilities, the reception centre for new arrivals, the busiest markets and taxi platforms for trips to Arua or all the way to Juba, and many of the RLOs, community initiatives, and important people, including the refugee leaders (both informal community leaders and those elected to represent the area).

3.1.2. Kenya

The research in Kenya focuses primarily on South Sudanese refugees in Kakuma Refugee Camp and Kalobeyei Refugee Settlement, which border each other, and includes a handful of households in Nairobi that have recently relocated from Kakuma or Kalobeyei. The camp in Kakuma opened in 1992 as a response to the large influx of refugees from the Second Sudanese Civil War (1983-2005). The camp hosts 225,625 refugees and asylum seekers from approximately twenty different nations. The majority (57.3%) are still South Sudanese, but other groups have arrived in large numbers from Somalia, DR Congo, Sudan, Burundi, Ethiopia, and Rwanda, and a few from Afghanistan, Syria, and West African countries (UNHCR 2025c). The camp is located a few kilometres outside Kakuma town, a small provincial town in Turkana County in the northwestern corner of Kenya, bordering South Sudan and Uganda.

Equivalent to one-third of Kakuma's population resides in Kalobeyei, which hosts 80,380 refugees

3 Land in this part of the West Nile area is held under customary tenure and owned by indigenous communities, administered through traditional governance methods, and passed on through ancestral lineages (O'Callaghan 2018, 20).

and asylum seekers. The majority (72.7%) are South Sudanese (UNHCR 2025c).[4] The difference between Kakuma and Kalobeyei is striking. Kakuma is overcrowded, hosting four times the population it is designed to accommodate (UNHCR 2025b); it consists of narrow dirt paths leading to packed marketplaces and residential compounds. Kalobeyei is more spacious and is structured along a tarmac road. In Kakuma and Kalobeyei, the research team engages with people from the Anuak, Dinka, Nuer, Toposa, Kuku, Acholi, and Kakwa communities.

3.1.3. South Sudan

Juba, South Sudan's capital city, has undergone rapid growth and hosts large numbers of displaced people, including people who have returned from life in asylum in neighbouring countries but are unable to return to their hometowns or villages due to flooding, continued armed violence, or lack of infrastructure, including health services and education (Berke and Larsen 2025, 7). The population in Juba ranges from people with good access to resources to many living in poverty. The infrastructure is not sufficiently prepared to meet the needs of the escalating number of Internally Displaced People (IDPs) and returnees; the challenges include establishing new livelihoods and accessing basic services (ibid., 2, 7).

The research in South Sudan focuses on South Sudanese who have returned or temporarily relocated to Juba, specifically from Rhino Camp, Kakuma, and Kalobeyei. The research is mainly conducted in Managateen, which is a large area, and in several other areas on the outskirts of town that host returnees from Uganda and Kenya. When the 2013-armed conflict broke out, a large number of evacuees (mainly belonging to the Nuer ethnic group) flowed into these areas. As a result, several formal and informal IDP camps were established. Originally emerging as a spontaneous settlement for Nuer-speaking IDPs fleeing the ongoing clashes, it is now a large-scale area resembling a shantytown on the outskirts of Juba.

3.2. Persons with specific needs

'Persons with Specific Needs' (PSNs) is a term used in the refugee context to identify people living with specific vulnerabilities, such as severe health conditions, because they are minors who have arrived without their parents, because they are a discriminated minority, because they are elderly, or because they are a single parent.

The designated protection partner to the United Nations High Council for Refugees (UNHCR) in the camps will identify these people according to specific criteria, and, ideally, they would be eligible for specific support and services that would lower their risk of physical, social, and mental harm.

In Rhino Camp, for example, PSN assessments are carried out yearly (UNHCR 2019, 2). The PSN category includes persons with serious medical conditions and persons with disabilities. Disability covers "physical, mental, intellectual or sensory impairments from birth, or resulting from illness, infection, injury, trauma or old age. These may hinder full and effective participation in society on an equal basis with others." (UNHCR 2019, 6–7). Serious illness covers a "serious medical condition that requires assistance, in terms of treatment or provision of nutritional and non-food items, in the country of asylum." (UNHCR 2019, 7). In an overview from October 2025, 12,059 persons in Rhino camp were categorized as PSN due to disability, while 5,515 persons were categorized as PSN due to serious illness (UNHCR 2025e, 1).

Compared to six years ago, the proportion of

4 The land on which Kalobeyei is located was formally handed over by the Turkana County Government in 2015 and developed in line with Kenya's commitment to the Global Compact on Refugees (GCR) and the Comprehensive Refugee Response Framework (CRRF), with the Kalobeyei Integrated Socio-Economic Development Plan (KISEDP) moving into its second phase (2023-2027) (UNHCR 2023).

refugees classified as PSN is much higher in 2025. In principle, the people with chronic disabling conditions that the research team engages with in the study would be categorised under the PSN category, because of their need for continuous daily care from caregivers. Yet this is not always the case, either because of a mistake in the system or because the need and impairment are disputed. Ideally, several services should be available, including specialised livelihood activities and support for shelter. In Rhino Camp, in contrast to Kalobeyei and other camp-based settings, refugees are expected to construct their own shelter. Over the years, humanitarian actors in the protection sector have constructed a number of houses across the settlement specifically for PSNs, commonly referred to as PSN houses. Some of these are strategically located near the health centres, allowing easier access to treatment.

In principle, PSNs are also prioritised when food and non-food items are distributed and supported with transportation to the distributions (UNHCR 2025d). How WFP differentiates food assistance according to the PSN category and different levels of vulnerability is, however, not fully transparent to inhabitants in the camps, which in turn can create confusion and mistrust (Brown and Torre 2024, 2; Schuler 2024, 41–43). Generally, the PSN term has two intertwined uses: a more popular use, as a term people employ in their daily language to describe anyone requiring specific assistance from humanitarian actors; and a more technical use by UNHCR and the protection partner, referring to the specific people selected for these specialised services. Obviously, these services have been severely affected by funding reductions, and in practice, specialised support for PSNs is very limited.

3.3. Food assistance

WFP provides food assistance to refugees in camps in Uganda and Kenya. WFP defines a 100 per cent food ration as equivalent to the minimum to sustain human life physically, which is 2100 calories per day (Schuler 2022, 452).

Food assistance is essential for refugees with chronic disabling conditions, as their ability to engage in income-generating activities or subsistence farming is very limited. In Uganda, funding for food assistance has decreased since 2020. The continuous shrinking of funding has sparked the introduction of 'prioritization exercises', which entail reducing food assistance and distinguishing between groups categorized according to vulnerability (Brown and Torre 2024). Already in 2024, the prioritization prompted a rise in crisis coping mechanisms such as casual labour and early marriages, which increase vulnerability to exploitation and abuse (ibid., 2). Further, consequences for health outcomes include malnutrition, undernutrition, as well as the inability to sustain medical treatment for people with medical conditions (ibid., 2).

Large reductions were made in March 2025 due to United States Agency for International Development (USAID) cuts. In Uganda, the most vulnerable refugees are supposed to be placed in category 1, which receives 40% rations; moderately vulnerable refugees are placed in category 2, which receives 22%; and the least vulnerable are placed in category 3, which is phased out of assistance (WFP 2025d). These are the lowest food rations WFP provides in East Africa. In May 2025, WFP reduced the number of refugees receiving aid from 1.6 million to 662,000. New arrivals receive extra food as well as non-food items. Currently, newly arrived refugees receive 60% rations (WFP 2025d). According to WFP, of the 690,282 refugees in 13 refugee settlements across Uganda who received assistance in May 2025, 307,699 received assistance via cash transfers, while 383,583 received assistance through in-kind food (WFP 2025d).

In 2025, years after the introduction of the prioritisation approach to food assistance in Uganda, camps in Kenya adopted the same approach. By August, only 69% of the refugee population in Dadaab, Kakuma, and Kalobeyei received food assistance (WFP 2025b). The most vulnerable (category 1) received 40% of the Minimum Food Basket (MFB), and the moderately

vulnerable (category 2) received 20% (WFP 2025b). Categories 3 and 4 have been phased out in practice, although category 3 might receive food once in a while (NRG 2025, 3). The prioritised approach to food assistance in Kenya continues to face several issues, including the misclassification of some vulnerable refugees into categories 3 or 4 (receiving no food assistance).

In Kakuma, WFP provides food assistance in the form of in-kind food distributions. As of November 2025, the 40% food ration for category 1 was supplemented with approximately 375 Kenyan Shillings (KES) (2.90 US Dollar) per month, while the 20% food ration for category 2 was supplemented with approximately KES 430 (3.33 USD) per month. In Kalobeyei, there is no food distribution. Inhabitants receive vouchers called 'bamba chakula' that can be exchanged for food items at certain shops. According to our data, as of November 2025, 40% of the food ration in Kalobeyei is equivalent to KES 1460 (11.31 USD), while 20% is equivalent to KES 915 (7.08 USD). In November 2025, households in category 3 in both Kalobeyei and Kakuma received around KES 530 (4.10 USD), but no in-kind food. This is considered an extraordinary ration that will not be provided continuously. While the provisions remain far below the basic survival needs, food assistance is expected to increase slightly by the end of the year[5], and more people will be transferred to a cash modality (NRG 2025, 3–4). Yet, malnutrition rates are rising (WFP 2025b, 1). With the humanitarian funding crisis, it is essential services, such as food assistance, that are reduced (Halakhe 2025, 4). USAID funded more than two-thirds of refugee food aid in Kenya, and more than 70% of education and protection services (ibid., 9). The devastating feeling among vulnerable household heads in Kakuma who have been placed in category 4 is well captured in an extract by a young poet in Kakuma (Kidi 2025):

Her children's laughter
echoed in the distance.
They hadn't heard
the sentence
passed in silence.

Category 4.
Like a disease.
Like a stain.
Like she didn't belong
in the line
for food.

Not sick enough.
Not vulnerable enough.
Not starving the right way.
Who decides
whose hunger
matters?

She held the ration card
like it could
rewrite her fate.
But the barcode
was already cold.
...
The pot was empty.
So was the jerrycan.
So was she.

That night
she made a choice.
Not to fight.
Not again.
She had marched.
She had shouted.

She had buried her pride
on the road
to the UN gate.

They listened.
They nodded.
Then they said
"There's nothing much
we can do."
...
That night
she bathed them,
kissed their foreheads,
and hummed
a goodbye
disguised as a lullaby.
...

She tied the curtain shut.
Took one last breath.
And left.
...
No note.
No scream.
Just silence.

But her silence
asks a question
louder
than any riot:
What breaks in a system
when a mother must die
for her children
to be noticed?

By Peter Kidi

5 By December 2025, the food assistance had improved to 60%, 40%, and 20% of the MFB for categories 1, 2, and 3, respectively (WFP 2025c).

In Juba, food assistance for returnees is largely absent, although some food assistance is provided to people in the protracted Internally Displaced Persons camps, the so-called POC (Protection of Civilians) camps. The little food assistance is decreasing, according to a newspaper interview with the Chairperson of Juba IDP Camps, who expressed deep concern about the lack of food aid in the camps, stating that no humanitarian organisation was providing food aid at that time (Juba Witness 2025).

People who return to Juba are mostly supported by extended family members, according to interviews conducted with refugees since 2022. Those who have no immediate network upon arrival need support during the first weeks in Juba and are often hosted in churches and supported with food on an ad hoc basis through private donations or charities. According to our interviews with community-based actors in Mangateen, no formal services, including food assistance, are provided; however, a large warehouse building serves as a temporary shelter for new arrivals. Some services are provided ad hoc by INGOs, charities, churches, and other humanitarian actors, such as vaccines at cholera outbreaks. According to a report from 2023, returnees in Juba report a high proportion of crisis or emergency food coping strategies, with 69% of the population reporting a crisis level of food insecurity according to the Reduced Food Coping Strategy Index (rCSI) (REF and Samuel Hall 2023, 50).

3.4. Income generation and coping practices

Most households followed in this study across Uganda and Kenya depend on various forms of food and cash assistance, as the majority are still classified as categories 1 or 2 based on their vulnerability.

However, as food rations have been reduced, many of the households are also dependent on remittances from relatives in South Sudan or on other support from relatives and community members in the camps. In addition to these coping practices, some of the households are able to generate an income; across all settings, small-scale businesses and casual work are becoming increasingly important as people cope with the new reality of the reduced food assistance. Other practices are also common, such as combining households.

In Rhino Camp, which is surrounded by fertile farmland, arrangements with local landowners are a common way to make ends meet as food assistance is being phased out. Since funding was reduced at the beginning of 2025, demand for farmland has increased. Generally, however, it can be challenging for affected households to engage in farming. The adults in this study often suffer from severe or multiple conditions, making physical labour challenging or impossible. Sometimes caregivers or other household members are able to farm or have a small kitchen garden; however, where there is only a sole caregiver, it can be very difficult to leave the chronically disabled person unattended. In Uganda, refugees are legally allowed to rear livestock in the settlement. In Rhino Camp, people mainly keep chickens, ducks, goats, and sometimes pigs. The 10x10-meter plots allocated to refugees are not suitable for keeping cattle. Over the past couple of years, as socio-economic conditions in Rhino Camp and the surrounding villages have declined, exacerbated by the aid cuts, goats have become a popular target of theft. Because of the high risks involved and the increasing poverty, goats have become a rare sight.

In Kenyan settlements, keeping livestock is forbidden, and farming is also restricted. The refugee legislation and encampment model restricts refugees from engaging in occupations reserved for the host community (such as collecting firewood, agriculture, and pastoralist activities). Therefore, refugees generally cannot engage in agriculture, except for small kitchen gardens (WBG 2024, 52). In Kakuma and Kalobeyei, farming activities are also limited by the climate of Turkana, which is semi-arid and prone to drought and floods. Refugees are allowed to rear chickens, though it is not common. However, several RLOs in Kakuma do engage in chicken rearing. There are, of course, always

exceptions to the rules, and a few courageous individuals bypass the rules and keep cattle or goats in their compounds, but generally, this is not currently practiced as an income or food source. In Kakuma and Kalobeyei, the main sources of income are therefore business, retail, and, especially, casual work, consistent with patterns observed among affected households in Rhino Camp, who were unable to farm. In Rhino Camp, some persons with chronic disabling conditions - or their caregivers - are able to have a small business, such as shoe mending, selling cut grass, charcoal or firewood, or having a small market stall selling vegetables. For instance, one patient with diabetes in this study was unable to engage in farming but was able to open a small shop for charging and repairing phones. Jack, another interlocutor with whom the research team has engaged for ADAPT (and many years before), is also trying to make a living through a small business in the same market. Jack lost one of his legs in the armed conflict and does not have any immediate support from family

Refugee hosting area in Nairobi @ Ayo Degett/DRC

members. Unable to farm, he decided to open a small shoe-repair shop, where he repairs shoes and sandals, earning a modest income.
With the changing conditions in the camps, informal, casual labour, known as *leja-leja*, is becoming the most common way to earn an income. Casual work for female refugees often entails domestic tasks such as washing and ironing clothes for private households or businesses in or near the settlement, supporting business owners in cleaning and drying cassava for resale, preparing food for street kitchens, or cleaning or sweeping compounds or shops. Women are also paid to help smear houses and fetch grass for roofing. Male refugees primarily engage in casual work outside the home, including small-scale construction work such as digging latrines and rainwater ditches, constructing mud or mudbrick walls, herding goats, or driving a motorcycle taxi, *boda-boda*, on a day-to-day arrangement with the motorcycle owner. Some of these types of casual work, which are physically demanding, are obviously not an option for people with severe chronic disabling conditions.

In Kakuma and Kalobeyei, the inhabitants come from a much more diverse range of national and cultural backgrounds, and therefore, the markets are generally much larger and more vibrant. Some residents in the camp seem to have greater access to income and remittances than others, creating opportunities for casual labour. For instance, in Kakuma, many South Sudanese engage in housework among the Somali families, who appear to have better access to remittances.

In Juba, there are some (limited) opportunities for engaging in casual labour. Men who return typically find casual work in construction, such as working as porters, building houses, or mixing cement (Omata and Gidron 2025, 113). Opportunities vary and fluctuate as does income, and 'contracts' may last from a few hours to weeks (ibid.). Female returnees often find work in small restaurants where they wash dishes, sell food on the street, or wash clothes in hotels or for individuals. Their income tends to be lower; however, their work tends to be more stable (ibid.).

Recent studies show that financially unviable conditions in camp settings and lack of livelihood opportunities push South Sudanese living in camps in Uganda and Kenya to engage in 'survivalist mobility' or 'distress migration', which, among other movements, entails returning to Juba to seek livelihood opportunities there (Gidron 2025; Omata and Gidron 2025; WFP 2025a; REF and Samuel Hall 2023). Since this was the case before the U.S. reductions in aid, distress migration can only be expected to increase under current conditions. Often, households engage in partial or split return, leaving some members behind in the camp settings while others return to Juba (Harpviken 2014, 57; REF and Samuel Hall 2023, 5). Typically, those who depend on services in the camp settings stay behind, such as children attending school or persons receiving medical care for severe health conditions (O'Byrne and Ogeno 2021, 760). Adult, able-bodied men are more prone to engage in distress migration (WFP 2025a). Those staying behind may receive occasional economic support from returnees, as money earned in Juba often 'funds' refugeehood (Omata and Gidron 2025). This is also the case for households affected by chronic disabling conditions, where one member may return to support the household member suffering from a chronic disabling condition, and the caregiver remains in the camp.

Woman selling vegetables at the market in a Ugandan refugee settlement @ Ayo Degett/DRC

4. Practices of care

4.1. Familial care relations

Lucy, a refugee in her 50s, finds her way to the shadow of a tree, supported by Kate, a much younger woman with a big smile. Lucy has diabetes, hypertension, and is paralysed on one side because of a stroke a few years ago. Kate supports Lucy as she slowly sits down on a plastic mat with a large UNHCR logo. Kate and Lucy are not related. In fact, they are not even the same nationality. Lucy is a refugee, and Kate is Ugandan but has been living in the refugee settlement in Uganda since she was a teenager and has three children with a refugee from the Upper Nile region of South Sudan. A few years back, Kate's husband left her and the children, and, finding it difficult to return to her village, she decided to stay in the settlement and found an incentive position as a Village Health Team (VHT) volunteer with an NGO focused on health. She worked as an outreach worker, visiting and supporting vulnerable patients on treatment, helping them back and forth to the local health centre, among other things. The monthly payment for VHT volunteers is modest (approximately 50,000 Ugandan Shillings (UGX) or 15 USD), but she found the work meaningful, and it brought food to the table.

Lucy was one of the patients she supported, and their bond grew closer by the month. As part of the devastating funding cuts, the health NGO had to cancel its outreach activities, and Kate lost her incentive job. Because Lucy had no one else to care for her daily needs, Kate decided to let Lucy move in with her near the health centre. Every day, she cooks for Lucy, attends to her personal hygiene, escorts her to the bathroom, and washes her clothes. When asked why she decided to take care of Lucy, Kate replies with a smile: "Ah, you know, God says that you should love someone like you love yourself. (...) That is why I saw the way she's miserable, that's why I decided to stay with her."

Many residents in Rhino Camp, Kakuma, and Kalobeyei need daily care to survive and lead dignified lives. Some, like Lucy, require support to perform most daily chores and maintain personal hygiene, and to gain access to resources. We define this recurring, daily, bodily, social, and emotional care as familial care. Compared with the other households in the study, the case of Lucy and Kate is somewhat unusual, as they do not have kinship ties. People like Lucy are typically cared for by female family members – daughters, mothers, nieces, etc. Lucy, however, had no relatives in the camp. Her daughter sometimes visits the camp, but does not stay for long, due to mental issues, according to her mother. Before moving in with Kate, Lucy was therefore looking into a harsh future, being fully dependent on the mercy of neighbours she did not know well. They might have been sociable people who could help her on an ad hoc basis, but that would not have provided her with much security. She found that in a familial relation – not the kinship tie with her daughter, but the kin-like tie she developed with Kate, with whom she now shares a household.

Based on engagements with the 37 households affected by chronic disabling conditions, it is becoming increasingly clear that caregiving is a part of life in the camp, at least for women. The vast majority of the households are female-headed (30 out of 37). It is viewed as a moral obligation to care for community members in need, often explained using biblical references, as did Kate. Primary caregivers view physical caregiving as being in line with their other obligations in life; it is not something they question or complain about. In April, when the visit to Kate's house took place, Lucy was still receiving food rations from WFP, based on her PSN status. She shared these with Kate and her children, who, in return, helped prepare the food and added to it. With the decrease in funding, Lucy was removed from food assistance in May, leaving her more vulnerable and dependent on her familial relationship with Kate.

Kate also visits another family living near her home, in an area adjacent to the health centre, originally designated for people who require frequent care, many of whom have PSN houses. The proximity

to the health facility and other key services is an advantage, but at the same time, a reason why some people see an opportunity to earn an income from renting out these PSN houses. Hajir, a mother of eight children who had arrived from Sudan a few months prior to the team's visit in April 2025, lived in this area. She had been advised to live close to the health facility as she has two young children (8 and 12 years old) with a severe mental health condition. Both of them are non-verbal, not able to cater for their own personal hygiene, hyperactive, impulsively aggressive, and prone to running off. By then, she was paying rent to the original tenant of the house, a chronically ill person who had relocated to town. This was a heavy financial burden for her, as she was alone with eight children and had no income and no immediate relatives in the camp to care for her and the children. Because she had just arrived, she received a more generous food ration for the first months, but by May 2025, her food assistance was set to Category 2, which made it difficult to feed her family and impossible for her to pay rent.

Hajir receives frequent visits from Kate, who also helps her with hospital appointments and occasionally cares for the boys at night to allow Hajir to rest, as they sometimes stay up all night due to hyperactivity. In addition, Hajir frequently receives visits from, a women representative, Brenda, who lives a few hundred meters away. In our engagement with Brenda and Kate over the past year, they have shown clear concern over Hajir's living situation. They had therefore contacted the NGO responsible for protection, OPM, and the RWC chairperson[6]. By May 2025, their lobbying paid off, and Hajir moved into a free PSN house, which means that at least she no longer needs to pay rent.

Kate's relation to Hajir has elements of the familial, although they do not share a household. The care pattern shows how different kinds of relationships overlap. Kate and Brenda are Hajir's neighbours and are sociable with a regularity that borders on the familial. At the same time, there is an institutional aspect of their relationship, in that Brenda is a member of the RWC and Kate was a VHT volunteer. Whether as quasi-family, sociable neighbours, or designated officials, they established links with institutions with resources that provided much-needed care in the form of housing.

4.1.1. Familial livelihoods

Several factors affect care in familial relations. Some are matters of personal chemistry: how well people get along. Others are matters of coincidence: who happens to be where. But most important for the everyday care in familial settings is the livelihood basis of the household. The team set out to explore how people with chronic disabling conditions were included in, or benefited from, three different types of income-generating activities: farming, herding, and small-scale business. Most camp-based families in Uganda benefit from some form of farm or kitchen-garden activities, including those caring for people with chronic disabling conditions. Kate, for instance, had access to a small plot of land and shared the produce with Lucy. This is not possible to the same extent in Juba and in Kenya.

In considering livelihood and familial relations, it is important to note that people with chronic disabling conditions try to contribute what they can. They are not just reliant on others for care. In fact, many people with chronic disabling conditions are themselves providing familial care for dependents. Looking across the data, small-scale business activities and non-intensive casual labour seemed to be their best options. This also became a way for Lucy and Hajir to diversify their income after food assistance became scarce. Lucy opened a small roadside shop, where she resold small portions of charcoal and sugar purchased in larger quantities at the market. Once settled into her new home, Hajir started producing mandazis (deep-fried buns), which she sold at the entrance of the reception centre, generating a small profit. Maria, a woman in her 60s with diabetes and hypertension, was able to open a small vegetable shop at the local market (with a small business grant from a humanitarian actor), where she sells vegetables for a few hours each day, as long as her energy allows. For Maria, the small daily profit is extremely important to sustain her life as she has no other sources of income and is caring for five of her grandchildren who were orphaned over the past couple of years. Under the current conditions, sitting in the shade of a tarpaulin selling onions and green peppers was a good option for her. The challenge Maria faces is that people in the Ugandan camps have less money

6 The Office of the Prime Minister (OPM) manages the coordination of core services in Rhino Camp together with UNHCR, handling all matters relating to refugees, including the determination of refugee status, allocations of land for the refugees and the coordination and management of refugee settlements. The RWC comprises elected refugee leaders who are volunteers, serving as the formal intermediaries between the refugee community and the Ugandan authorities and humanitarian actors.

to spend on vegetables, which are perceived as luxuries during periods of extreme precarity.

Lydiah, a South Sudanese refugee in Kakuma, almost the same age as Lucy, suffering from the same chronic disabling conditions (diabetes and hypertension), has also experienced the heavy reduction in food assistance. Like Maria and many others with chronic disabling conditions, she is the breadwinner of the household and must care for her older sister and several grandchildren between 12 and 17. Because Lydia lives in Kakuma, farming and small-scale business are not options due to the lack of farm land and the distance from her house to the market. To earn an income, Lydiah walks several kilometres every morning at sunrise to the Somali neighbourhood of the camp, where she offers to perform housework, such as washing dishes and laundry, or cooking. In return, she receives in-kind items, such as a cup of beans, a small piece of soap, or a bottle of cooking oil. By noon, she returns home to rest and spends the rest of the day on her mat in the shade, re-charging and resting from dizziness and other symptoms of her hypertension and diabetes. Her care for family members consists of earning a small income so that others do not have to, and so that the children can continue their schooling.

The cuts to food assistance and support services in 2025 have affected people with chronic disabling conditions and their households significantly. It has placed additional pressure on their ability to limit expenses and, if possible, generate income. People employ multiple simultaneous coping practices. It is worth noting, however, that few people are able to make ends meet. For those with specific dietary needs, such as those living with diabetes, it is becoming increasingly difficult to eat according to the diet recommendations. Eating frequently is difficult when you are poor and need to skip meals, and the recommended diet is more expensive than the food poor people survive on, mainly porridge made from maize flour.

In urban settings, the livelihood basis of households with chronic disabling conditions is different. All the urban refugee households affected by chronic disabling conditions that the research team has engaged with in Kenya and Uganda receive financial support or free accommodation from friends or relatives. In Nairobi, the research team engages with 4 households affected by chronic disabling conditions who are all living in a neighbourhood on the outskirts of town, close to many other South Sudanese. For these families, the rent is considerable, about 12,000 to 20,000 KES (approximately 95 to 160 USD)—higher than in other towns. All of them received remittances from a family member in South Sudan or abroad on a semi-regular basis, but only enough to cover rent, leaving them in a precarious position to afford medical care, transportation to clinics, and food. Two of the households reported that they received support from an elderly family member who was sick or recently passed away (which put an end to the flow of remittances), putting them in a dilemma between moving back to South Sudan or back to the camp, where their food rations have been cut. As we will return to in the sections below, dependence on remittances is not secure because it is contingent on the health and stability of a specific family member, often referred to as the ‘sponsor’. While proximate familial relations provide everyday care, the household’s economic foundation rests on more ad hoc, sociable relations with distant sponsors.

4.1.2. Mobility

Sara, a young woman in her early 20s, lived permanently in Rhino Camp since the outbreak of violence in Juba in 2016, through 2021. During these years, she lived with and was the daily caregiver of her mother, Esther, who is suffering from chronic pain and fatigue, and her older brother, Juol, who has Down syndrome. Sara completed her secondary education in Rhino Camp, but as she finalised her studies, Uganda introduced the prioritisation approach, and the family was placed at the lowest level of food assistance. Sara is an energetic young woman with many good ideas for income generation and decided to move to Juba to fundraise for her family members left behind in the camp. But as Esther's health deteriorated, she decided to move her and her elder brother to Juba. Both of them needed daily care, and although she had left them with some young nieces, she felt they were too young for the responsibility.

By that time, Sara had secured a rare salaried job as a waitress and was able to make ends meet for the household financially, although she was away from home more hours than when they lived in Rhino Camp. Juol enjoyed taking short walks, and he continued to do so after they moved to Juba. One evening in Juba, he did not come home. He simply couldn't find his way back and ended up sleeping on the streets. In conversations with the research team, Sara explained that this would never have happened in Rhino Camp, as people would know where he lived and would walk him back if he became lost. Fortunately, a woman who used to live in Rhino Camp found him on the street, recognised him, and called around to find Sara's phone number, and eventually they were reunited.

Shortly after this incident, Sara was requested to come and stay with her father in his village in the northern part of South Sudan. According to her, she was miserable leaving Juol and Esther behind once again, and also afraid of the father's motives, as it is not uncommon to marry young women off. She was finally allowed to return to Juba, but the political developments there were making her nervous, and in early 2024 she therefore decided, in consultation with her father, to take Esther and Juol back to Rhino Camp in case the situation in South Sudan escalated. Because of the very limited income opportunities available in Rhino Camp and the status quo in Juba, she decided to return to Juba with her mother and brother in the last quarter of 2025. She found a clay house in a calm neighbourhood where the family could live for free with extended family members, with additional precautions regarding Juol's mobility. Sara now earns income by re-selling clothing, which she markets on TikTok, thereby affording her sufficient flexibility to provide daily care for Juol and Esther.

Because people living with chronic disabling conditions in this displacement context are so dependent on basic needs, they sometimes need to move to stay close to the people and structures caring for them. This was the case for Juol and Esther, similar to many of the people with chronic disabling conditions with whom the research team engages. In Uganda, grandmothers in need of daily care are moved back and forth between family members in town and in the settlements, depending on resources and the availability of caregivers. And family members in South Sudan who fall seriously ill or for other reasons need daily care are often brought to relatives in Kenya or Uganda because access to medical care is better than in the South Sudan village and cheaper than in Juba.

Our tracking of the same 37 families shows the extent to which family members with chronic disabling conditions move. More than half of them needed to move to urban areas or to South Sudan in 2025 (see Figure 2). Their movements are often pendular: some remain in Juba or in urban areas of Uganda and Kenya for a period, then return to the camps, and sometimes relocate again. Although moving is physically and financially exhausting for the affected households, several of them have shifted locations multiple times. The primary reason for their movements to urban areas (Arua, Kampala, Nairobi, and Juba) is to seek medical treatment, but they also relocate due to the high food insecurity in the camps, to seek support from relatives, or to find a way to earn an income.

Figure 2:
Mobility of household members during 2025

4.2. Sociable care relations

In the current economic situation for South Sudanese displaced inside and outside South Sudan, most able-bodied family members must contribute to the income of the household to make ends meet.

Caregiving puts extra pressure on breadwinners and already fragile household economies, and families do their best to balance caregiving with income generation inside and outside the camps, which sometimes requires pendular movements for the people they care for. While this is a necessity, the social networks and sociability in these locations play an important role in the regular support of these families, in addition to the primary caregiving. As seen in the episode with Juol, he was safe to wander about in Rhino Camp, where sociable people knew him and brought him home if he got lost. But in Juba, he was a stranger and would not be cared for in the same way. The same was the case for Hajir, who was new to Rhino Camp in early 2025, when the team began engaging with her. Her two sons would sometimes run off, but because they were new to the settlement, people did not know them; they did not bring them back and might even discipline them because they did not understand their condition.

All the families we have engaged with in 2025 value staying in one location and building trusting sociable relationships with neighbours, community structures, and local leaders, exactly because their living conditions are more precarious and they tend to need more support from others. An elderly woman, Rose, suffering from diabetes, expressed it this way:

> *"There [in Juba], everyone is busy, no neighbours care or even come to visit me like here in Rhino Camp".*

Rose decided to move to Juba to seek better income opportunities upon being phased out of her food assistance in 2025, but quickly decided to return to Rhino Camp, despite the hardship related to a lack of food rations. All in all, the mobility patterns of the households and daily caregivers of people with chronic disabling conditions bring constant dilemmas. On the one hand, increased economic pressure on households forces more caregivers to relocate for income opportunities; on the other hand, families affected by chronic disabling conditions benefit greatly from the stability provided by long-term, trustworthy relationships in one location. Sociable relations of care are necessary supplements to familial relations.

A late afternoon, as the sun was setting at the far end of Rhino Camp, two members of the researcher team arrived at Peter's compound. Peter, a young man in his early 20s, lives with his single mother and five younger siblings in a clay house. From a quick glance at their houses and sparse household items, they seem to be among the poorer residents in the area. Peter has suffered from mental illness for years, and even though the family had sought help from medical centres and hospitals, the man continued to see things and hear voices, which at times made him act aggressively. From the engagement with Peter over the years, his own main concern is his earlier diagnosis of sleeping sickness, which affected him as a young teenager; the voices and visions were also bothering him at times, but they could also calm him. Physically, he was tall and strong, but according to himself and his mother, his mental condition made it impossible to undertake farming activities and other household chores and casual labour that could support access to resources.

The research team had come to learn more about a specific afternoon a few months earlier. In a quickly escalating situation, Peter threatened his mother with a knife, and while the mother tried to escape, he cut up plastic chairs in rage. Neighbours heard the noise and immediately called the block leader, who could not calm him down, and had to leave the scene when he was threatened with a hoe. Peter's younger brother arrived and ran to the local motorcycle taxi station to seek assistance. Within a few minutes, fifteen motorcycle riders arrived and managed to calm him down enough to tie him to the back of a motorcycle and transport him to a health centre, before the police arrived at the compound. With help from the motorcycle taxi riders, the health personnel managed to give Peter an injection with a tranquilliser that calmed him down. After the incident, once Peter was calm and composed, he was taken to the local church, where the priest attempted to expel his evil spirits and offered comfort.

Individuals and semi-formal community structures play an important role in the care of people affected by chronic disabling conditions. In the case of Peter, the motorcycle taxis consisted of a group of men who know Peter and his younger brother, and the issues the family is facing. During the research team's engagement with them, they explained that they preferred not to involve the police, as the local health facility was a better option for calming Peter during his episodes than a detention centre. The sociable care provided by the motorcycle drivers is different from the regular daily care provided by Peter's mother and other primary caregivers of people with chronic disabling conditions. The second kind of care relationship is based on the sociality of the community in which they live their lives. We refer to it as sociable because it arises from the condition of living together as social persons who recognize and respond to needs, as exemplified by the motorcycle taxi riders. The act of care depends on the situation and on the community members' or group's ability, attention, and resources. For the motorcycle taxi riders, Peter was a community member in need rather than a taxi customer. Later, they brought him to a priest, who often talks with Peter and supports the family, because he cares and has built a relationship with them over the years.

4.2.1. Local business owners and organisations

Local businesses and business owners are often supportive and provide specific attention to families and individuals living with chronic disabling conditions. It is common that families who are hit by food insecurity, especially those with other vulnerabilities such as disabilities, can buy food on credit or receive a small in-kind donation here or there from shops at the market. According to our data, this is more common for families who are well known in the local community and have lived there for many years.

This is the case for Ayak, a young woman in Rhino Camp, born with CP, non-verbal, and suffering from frequent epileptic seizures. Although her mind is quite affected by her condition, she moves around Rhino Camp and is able to pick up her medicine at the health facility a couple of times a month. Her own household is struggling with food insecurity as her parents are old and have limited access to resources. When they are out of food, she walks to a neighbour's home to eat and is rarely turned away. She likes to go for walks and hang out in the busy junction next to the market; she is known to most people and is described as happy, social, and looking to engage with others. When she is hungry, she asks local businesspeople for food or money, and, according to friends and family, she always

finds those willing to provide it. As her father explained in an interview in April 2025:

> *"She is like this: If she is hungry and there is nothing to eat, she goes to Ocea [another zone in the camp]; there, a lot of people give one thousand [UGX], one hundred [UGX], she helps herself with it."*

The local shop owners are not the only local businesses that care for her. There have been times when she has had a seizure and when she could not find her way back home afterwards. In these situations, people have offered their assistance, especially local motorcycle taxi riders, who bring her home when needed.

The support and care provided by local businesses are not unique to the case of Ayak. Our data shows that many other people with chronic disabling conditions living in poverty are given free rides with motorcycle taxis, discounts at the market, and support by casual labourers who would otherwise have charged for their services. However, the economic situation is changing, and in interviews, business owners and community members explain that, given their own economic circumstances, they cannot provide the same level of financial support as before. As explained by Brenda, Hajir's neighbour, who has been removed from the food assistance herself and is increasingly frustrated with the situation:

> *"What I have is little, and also, I have to share it with others. Yeah. For example, you don't have salt... I also have little, I will give you a little, you might use it for one to two rounds to cook. What about the next? I have the heart to help, but what I have is not sufficient."*

Man grinding cassava flour in a Ugandan refugee settlement @ Ayo Degett/DRC

Across the research locations, the research team is engaging with local CBOs and RLOs of varying sizes that are implementing activities at different scales. Some of these have a specific focus on persons with disabilities or other chronic conditions. In Rhino Camp, the research team has engaged with a local organisation that, among other activities, is implementing farming activities for people and households with chronic conditions. Every year, they negotiate a piece of land with the host community and organise for these affected families to be given seeds and tools to plant crops that will support their food stock.

Another small-scale organisation the team is following is a rice-farming initiative. The organisation, a collaboration between the refugee community in Rhino camp and the host community, comprises 210 members, divided into seven subgroups. To increase household consumption and market sales, the members received training in cultivating specific cash crops. The association stores seeds for the next year, and farmers store their produce at home and decide on how much to sell and how much to consume. The organisation explicitly focuses on alleviating food insecurity among vulnerable people, including those with chronic conditions. The association matches resourceful farmers with vulnerable persons, who then farm in groups. With small-scale financial support from international donors, the association rents a tractor to open two to three acres of land per person. Seeds and other materials, such as a rice mill and sacks for storage, are also provided for the members, and connections to the markets are part of their activities. They have also established a Village Loans Association (VSLA) through which members can take loans and repay them at low interest. Members who have a chronic condition can borrow without interest, and in some cases, they are exempt from repaying their loan. Furthermore, they can have the land opened free of charge, whereas other members must pay to have the tractor plough their land. In an interview, the chairman explained how this idea came about:

> *"We said, okay, now, what can we do? We are all one, we are all together. Okay, now, if this is how our brother or our sister is..."* He points to the members next to him who suffer from chronic conditions, including a man with a walking impairment, and continues: *"Now, how about me in the future? So, I think, what we have to do is, we have to help him [or her]".*

The chairman highlights that anyone can potentially become vulnerable and unable to farm. Therefore, the association began with a vision to include individuals with chronic conditions. Yet, the funding cuts have also affected the association's ambition to scale up farming activities that could help manage food insecurity among these vulnerable households.

4.2.2. Informal groups and associations

The care from informal groups and associations takes many forms. It can be more ad hoc, as seen in the episode with Peter (who had a mental breakdown), but it can also take a more regular pattern. The data collected through 2025 portrays a wide variety of support and care practices by informal groups and associations, supporting their fellow community members in need. The research team has followed the above-mentioned motorcycle group for a long time (Degett et al. 2024). Some years ago, they made a specific commitment to help vulnerable community members through different supportive initiatives, such as constructing shelters, digging latrines, and transporting people to the hospital at no cost. Many similar groups exist in Rhino Camp. One of them is an association of men who identify as former alcoholics and have a common goal of supporting the most vulnerable with hard labour, such as digging drainage canals and latrines for families with chronic disabling conditions. In Rhino Camp, we have followed a group of young people who compose songs about peace while also organising an emergency food stock system that enables vulnerable, food-insecure people in their community to access food during hardship. In both Kenya and Uganda, we see many examples of women's groups that support one another financially and otherwise during precarious times, by means of VSLA approaches. In these groups, members can borrow money to pay hospital bills and medicine costs, as well as transportation for check-ups at health facilities. When members are admitted to the hospital, the group often sends a representative with food and comforting words. Some more informal savings groups also support community members. This was the case for Jacob, a young man with suspected diabetes who has been suffering from a wound on his leg that cannot heal:

> *"Last year, there was a group of women in our community. They helped me. I think they've been contributing those money themselves. Then they came here to me. Then they give me. Tell me that just go for treatment. Yeah, I went there, I spent almost one week. Then at least I get my body have changed. Yeah. That was last year."*

The group of women had seen Jacob suffering and supported him to get some treatment, which made his leg better for a little while.

Many of the community-led initiatives that care for people with chronic disabling conditions support them with access to resources and food. One of these long-term, regular support initiatives is the joint cattle-rearing initiative in Rhino Camp. This initiative is unique in many ways. Since the early 1990s, six extended families from the Dinka and Nuer communities have herded cattle with local landowners. Young men from the surrounding villages take the cattle for grazing every day, keep the kraal swept, and the cow dung heaped. In return, families of the young men receive an agreed-upon number of cattle born from the herd and a portion of the milk produced by the cattle every day. In the afternoon, children who are hungry, people living with disabilities, elderly people, and families experiencing severe food insecurity line up to receive a cup of fresh, warm milk.

4.2.3. Churches and faith-based communities

Churches and faith-based groups, such as women's bible groups, play an important role for many people with chronic disabling conditions. As seen in the description of the care provided for Peter, when he has a (psychotic) episode, one of the first people involved is the local priest. The research team has also documented how churches often provide care through resources, such as in-kind donations to the most vulnerable or hot meals. The families with chronic disabling conditions that the team is following in towns all report that regular donations from local churches are a key pillar of their access to resources. Churches and church groups are also among the first to respond with resources or shelter in cases of emergency, such as when people lose their homes to a fire or are robbed.

A good example of this is Lucy, the older woman with diabetes, hypertension, and paralysis, cared for by her neighbour, Kate. After she was removed from food assistance, she tried her best to make a living from reselling household items. One day, however, her home was broken into. She did not know who broke in, but her hard-earned, modest savings from selling charcoal and other household items were stolen. Lucy could not see how she could recover what was lost. But upon hearing of the robbery, members from her church congregation paid her a visit. In addition to their emotional support and comforting words, they had collected 100,000 UGX, which she could use to restart her charcoal business. Deeply grateful for the support, she explained that she had considered reporting the incident to the police but did not do so, as she did not expect it would enable her to retrieve what was lost. The church's offer of support appeared to heal the wounds of the robbery more effectively.

We have called these relations of care 'sociable' because, by and large, they are based on community rather than being formally authorized for care. Their help is part of the general social relations that shopkeepers have with their customers and churches have with their members. Initiatives such as the rice project were not explicitly formed to help households with chronic disabling conditions, but they did include special attention to them. The same holds for the motorcycle taxi group and the joint cattle grazing arrangement. In managing their resources, they consider the needs of people with chronic disabling conditions, often on an ad hoc basis as situations arise, and to the extent that they themselves have enough to share.

4.3. Institutional care relations

We consider institutional care relations to be more formal than familial and sociable ones. Their primary purpose is to provide a service of care, for which there are rules, guidelines, or procedures. They are professionalised, at least to some extent, and they are backed by some resources for undertaking their work.

They are legitimized by state recognition. Yet, these institutions are not entities unto themselves. They are embedded in society and in other relations of care. As we have seen, an element of familial and sociable care is the effort to connect a needy person to institutional care. Seeking treatment, support, and health care often depends on relatives, neighbours, and community members. They are the ones who accompany people with chronic disabling conditions to health clinics, provide transportation, or pay medical bills. In another sense, institutional care is not monolithic. Within institutions, actors differ in how they provide care. Some go beyond the guidelines to provide extra help, while others fail to meet their responsibilities.

4.3.1. Health facilities and formal structure

In Uganda, healthcare services in government and partner-operated facilities are accessible to refugees at no charge. Refugees in settlements share health facilities with the local host population. Uganda has a tiered, referral-based health system (Tsui 2021)[7]. The lowest level is the VHT member, who is typically the first point of contact for people in rural areas and refugee settings. VHTs are lay community-based volunteers who are briefly trained, either by the Ministry of Health or an implementing NGO, to advise patients and refer them to health centres (Tsui 2021, 26). The health centres in Rhino Camp offer basic primary healthcare, including laboratory services, maternal care, and treatment for common illnesses such as malaria, respiratory infection, HIV, diabetes, tuberculosis, and hypertension. There are three Health Centre IIIs (HCIIIs) in Rhino Camp: two in Ocea and Ofua run by an international health NGO, and one in Olujubo run by government. This international NGO is currently the main 'humanitarian-funded' healthcare provider, operating in partnership with UNHCR. As part of the scale-down on activities, the NGO has handed over all activities in Olujubo to the Ugandan government, which, due to funding shortage, has lowered the capacity from 30 to 11 healthcare staff, according to our research. In addition to the HCIIIs, a small mobile HCII unit based at the reception centre focuses on new arrivals. The closest referral hospital is the Regional Hospital in Arua.

In Kenya, the 2010 Constitution stipulates the right to health care for all persons, including refugees assigned to live in camps (Jemutai et al. 2021, 4). However, according to our data and literature on the topic, there are barriers, including drug shortages, documentation requirements, the threat of harassment, and language barriers (ibid.). The primary healthcare system is decentralized, with 47 counties managing their own healthcare services (Okello 2024, 22). Refugees in Kakuma and Kalobeyei share health facilities with the local host population, just as in Uganda, and the Ministry of Health (MoH) works with two implementing international NGOs, UNHCR and other partners, to ensure that these health services are financed and operational. In Kakuma and Kalobeyei, health facilities include one general hospital, two health centres, and five dispensaries (often referred to as 'health clinics') (UNHCR 2025a)[8]. Because Kakuma and Kalobeyei are more densely populated than Rhino Camp, residents have shorter distances to health clinics, but capacity remains stretched (Jemutai et al. 2021, 5; Okello 2024, 22). Similar to the VHTs in Uganda, community members trained as CHPs play an important part in the daily healthcare structure in Kakuma and Kalobeyei, conducting outreach activities and providing basic health services such as home-based care, disease surveillance, and community education

7 The health system includes health centres II (HCII), which are outpatient clinics run by nurses, where they treat common diseases such as malaria and offer antenatal care (Tsui 2021, 26). Typically managed by a clinical officer, health centre IIIs (HCIII) provide general outpatient clinic services, basic diagnostic services, and have a maternity ward with basic emergency obstetric and newborn care (ibid., 26). Health centre IVs (HCIV) serve a county and operate as mini-hospitals with surgical capacity as well as a senior medical officer and another doctor (ibid., 26).

8 The two health centres provide comprehensive maternity services and both centres have maternity wards. The general hospital provides full in-patient services, has a surgery theatre and imaging services (ultrasound and x-ray) (UNHCR 2025a). In case of emergency medical need (lifesaving or to prevent permanent disability), UNHCR and health partners can refer individuals for treatment in Lodwar or Nairobi.

and awareness campaigns (Mangeni et al. 2016, 4). The main populations served by CHPs are young children (below 5 years), elderly people, pregnant women and breastfeeding mothers, people with disabilities and chronic illness, and people with mental illness (ibid., 4).

In South Sudan, the quality of public healthcare is low compared to that of Kenya and Uganda, and entirely dependent on support provided by international agencies (REF and Samuel Hall 2023, 44). Interviewees in Juba over the past year report that private health clinics are perceived to be somewhat cheaper than those in Uganda. Refugees who need relatively simple procedures – and can afford it – may choose to have them performed in Juba or the DR Congo, which has occurred in five cases recorded over the past year among the families the research team is following. In urban centres such as Juba, access to health services may be somewhat better than in other areas in South Sudan (Berke and Larsen 2025, 3). While private clinics are perceived to be cheaper than those in Uganda and Kenya, they may still be costly. Some return to access traditional treatments.

4.3.2. NGOs and outreach work

Health care is not the only support offered by formal actors to those with chronic disabling conditions. National and international NGOs provide food and disability aids such as wheelchairs and accessible latrines. Some organisations also supply food items, although it is not their primary function. One NGO focusing on psychosocial well-being delivers mental health care and treatment for people suffering from mental illnesses. They supported Hajir, whom we introduced previously, because she has two children with mental health conditions. The medications given to the children increased their appetite, and Hajir contacted the NGO, hoping they would support her. A staff member from the organisation visited to review the situation, and Hajir received a one-time in-kind donation of posho, rice, cooking oil, and beans. These extraordinary services, however, appear to be dwindling with reduced funding, as illustrated in the following example: Lucy, whom we introduced previously, was supported by a cluster leader within the Ugandan RWC structure.

Peer researcher conducting research in a drug shop in a Ugandan refugee settlement @ Ayo Degett/DRC

It was a Saturday morning when Hamza mobilized a group of boys to come and excavate a pit latrine for Lucy. Although Lucy had been permitted to use her neighbour's latrine, her chronic conditions had placed a strain on this arrangement. The paralysis of the left side of her body affected her mobility, and therefore, she sometimes created a mess in the latrine. This had caused tension between Lucy and her neighbour. Initially, Lucy tried to seek support from humanitarian organisations, but none of them had the resources to help construct a latrine for her. Lucy approached the cluster leader, Hamza, for support, and that Saturday, he arrived with a group of boys who had been helping the community by constructing toilets at a lower cost. The boys asked Hamza, "Sir, who is going to pay us because this woman looks vulnerable." Hamza replied, "Let us help this mama like we are doing it for our own mother because I even don't have money to pay you people, that's why I said I will give you lunch and breakfast". Although the boys were also in a difficult situation, they decided to do the work because of Lucy's condition. Hamza began digging the pit with the boys, and late in the evening, he walked from home to home, asking community members for contributions to raise enough money to purchase a plastic toilet slab to cover the pit. After three days, the latrine was constructed, and Lucy appreciated Hamza and the boys for supporting her.

As humanitarian support is being phased out due to funding shortages, structures such as elected refugee leaders are becoming increasingly important. Their engagement and the type of support they can offer, however, are variable. As we showed in a previous section, some community leaders, such as the women representative, Brenda, are very engaged and find it important to make frequent visits to vulnerable households. They also provide direct support on a more irregular basis, as illustrated by the case of Hamza and Lucy. While the CHPs and VHTs work on incentive contracts, the elected refugee leaders are volunteers. For both structures, the engagement and approach can vary. Some CHPs, VHTs, and refugee leaders may check in often, visiting households affected by chronic disabling conditions to check up on their situations and needs and provide direct support. Others are not as involved. It is important to note that since they are part of the community themselves, they have also been affected by the reductions in food rations, and especially refugee leaders who have been phased out of food support entirely have had to prioritise their own Income Generating Activities (IGAs), sometimes affecting the time available for their position.

4.3.3. Accessing institutional care

Receiving support sometimes depends on your ability to actively seek it and on knowing whom to approach (refugee leaders or humanitarian organisations). For some - especially those who have stayed in the camp for a long time - this may not be a challenge, but for others who have a limited social network or support, it can be.

West of Arua city, Mary, a South Sudanese refugee in her late thirties, is staying with her son in a house rented by Elizabeth, an elderly refugee woman from the same ethnic group. Both women are registered as refugees in Rhino Camp but stay in Arua due to health conditions. Mary's son, Gai, is suffering from a developmental disability, and despite being 14 years old, he cannot walk or speak and requires constant care. Mary lost her husband during the outbreak of war in 2013 and fled to Rhino Camp with her children. In addition to his developmental disability, Gai was diagnosed with tuberculosis a few years before our visit and referred to the main hospital in Arua for treatment. Mary felt that she had no other choice but to move into town to stay closer to the hospital. Fortunately, Elizabeth allowed her to stay in the house at no charge because of the boy's condition. Five of Mary's children have remained in Rhino Camp, where neighbours look after them. Every month, she travels to the camp to check on her children and to receive the food rations on which the family depends. She used to supplement her food rations with remittances from her uncle in South Sudan until he passed away recently. As the food rations are being phased out, Mary is continuously considering her options for alternative income. Farming could be a good option, but not possible while she is in Arua, and which other options are left: "I am not an old woman. If I go to [South] Sudan, I will [get] another husband, why not?", she laughs and afterwards she notes that at the moment, it is not safe to return, and she cannot leave Gai behind.

Access to care at health clinics and from specific health actors is often essential for households affected by chronic disabling conditions. For Mary and her son Gai, it has been necessary to relocate to Arua to access this institutional care at the hospital there. Had it not been for Elizabeth, the high rent in Arua would have made relocating difficult. Transporting Gai back and forth is more costly than Mary can afford. The case illustrates that seeking treatment in the formal health care system - at least for the group the study concerns - often depends on other relations that support the process with resources and logistics.

Similar types of support are provided to all other families affected by chronic disabling conditions that the study is following in the urban areas. The families in Nairobi were able to access treatment options only because of financial support from family members.

As the quote at the beginning of this section highlights, access to health care also depends on the mobility of those in need of medication or treatment. In the study, 9 people with disabling conditions (and their closest caregivers) shifted location at least once during the first year of the project: some travelled back to South Sudan, and some to urban areas outside of the camps, for the most part to be closer to health facilities while receiving treatment (some very vulnerable and elderly also stay for longer periods or permanently). Much of the specialised care is located in the big cities; refugees relocate to Nairobi and Kampala for medical care not available in the camp. Intimate others typically make decisions on where support and healthcare for those with chronic disabling conditions can best be accessed. For instance, although the quality of healthcare is poor in Uganda, it is still better than in Juba, where one must pay for everything. Therefore, poor households in South Sudan send relatives to Rhino Camp if they are sick because the public healthcare is better and cheaper than the public healthcare in Juba, and because the options in the villages are limited. Going to South Sudan for health care is often the last option; however, it seems traditional treatment is more available in South Sudan than in the camps. In Kakuma, a 22-year-old man suffering from mental illness ended up being transported to South Sudan. He did not always have this condition; however, one day, he suffered from an episode similar to malaria fever. From then on, he began having hallucinations, losing his memory, having trouble recognising people, and speaking at length about things that were incomprehensible or happened long ago. A CHP referred him to the clinic, where he was given malaria tablets, which did not help. A community clan association lent money to the man's family, enabling them to take him to the Kakuma Mission Hospital. Still, nothing helped. His family was advised by an elder that he must have been bewitched, so two relatives escorted him to Juba to see a witch doctor. He is currently still in Juba getting traditional treatment.

As we have shown, access to institutional health care often depends on relationships that facilitate it. Sometimes these are not the daily familial ones, but rather ad hoc support from a relative abroad or a one-off loan from the Community Clan Association. What matters is the quality of a relationship to someone with resources that can be useful: means of transportation, remittances for hospital bills, and social status and networks to solicit contributions and mobilise community members to support.

4.3.4. Effects of the funding cuts

In the refugee settlements in Uganda and Kenya, healthcare has been deeply affected by the funding cuts, drastically changing the availability of care. A healthcare worker in Rhino Camp expressed his concerns with the funding reductions in an interview in April:

> *"The impact is already great on healthcare (...) We have an influx of refugees at an average of two hundred at the reception centre. All this is competing with already very limited resources. So, the impact is already very great and we are anticipating community deaths because... it makes no sense... when I come to a health centre and I go back without medication.... So, clients now feel 'even if I go I have no medication - I rather remain at home.' So, there will be more community deaths, and more community deaths simply mean system failure. Yes, it is better to have patients dying in the health centre than dying from the community..."*

The predictions made by this healthcare worker turned out to be true. As humanitarian funding for the public health facilities in the settlement declined, medications were running low, and many patients stopped attending. In both Kenya and Uganda, U.S. funding has been a key pillar of health care provision in refugee settings. The international NGO that manages the healthcare services in Rhino Camp lost almost half of its funding in 2025, and the specific funding for their Uganda activities was among the directly affected (Loy 2025). The U.S. funding cuts have also heavily

affected the refugee response in Kenya, including health services, essential medicines, diagnostics, and supplies (Halakhe 2025, 11). In Kenya, more than 300,000 people are estimated to be affected, and health facilities are at risk of closure (NRG 2025, 8). Further, organizations document declining immunization, rising maternal and neonatal mortality risks, and declining Tuberculosis (TB) and HIV adherence (ibid). Among the long-term consequences of the aid cuts, the NGO Refugee Group (NRG) foresees that preventable outbreaks will occur, the general public health will be weakened, and protection risks will be heightened (NRG 2025, 8).

The recent aid reductions have also affected the community health care mechanisms, namely the CHPs in Kakuma and Kalobeyei, and VHTs in Rhino Camp. VHTs and CHPs are more affordable; therefore, the structures may rely more on them, despite their not being authorised doctors or nurses (they do have a background in health, nutrition, or other relevant areas). They are also being reduced, increasing their workload. Timely referrals depend on these community health structures. VHTs and CHPs are generally meant to keep an overview of a block or area of the settlement, especially on those who are chronically ill, malnourished, pregnant, or postnatal. Although referral mechanisms are currently in place, it is uncertain whether they will be able to continue. In Rhino Camp, outreach activities currently rely on VHTs, and the reliance on incentive workers may make outreach uneven across the camp. At the same time, the number of VHTs is expected to decrease, with the average ratio of VHT to community member going from 1:600 to 1:1000 (REACH 2025, 5). In addition, several health programmes have been suspended or disrupted as a consequence of the aid cuts, including disability-related programmes and HIV/AIDS programmes (REACH 2025, 5). In Kenya, CHPs have been laid off, and since they are typically the first line of response and responsible for essential interventions for vulnerable refugees, this will have immediate consequences for the health outcomes of the most vulnerable refugees and create cascading effects over time (Halakhe 2025, 9). Paul, a South Sudanese refugee in his mid-forties, has worked as a CHP in Kakuma for about ten years. He has a background in nutrition and medical assistance, and he is also, himself, suffering from a chronic condition. When asked about the effects of the funding reductions on health services, Paul takes himself as an example:

> *"I have a kidney disease… when I went to [the] clinic, they just scanned… But I didn't get the services. Up to now, that condition is killing my body. Last time they promised me, (…) maybe if you are lucky, you will be transferred to another, further treatment … So even now, I will never get the chance to operate that problem. So … it is not enough or it is a lack of medicine. If there is enough, it is supposed to be cheap. I'm working as a health worker, but I didn't get support for the problem that I have."*

Despite Paul's position as a CHP, he is struggling to access the proper health care for his own condition. In the face of aid reductions, access to medication is currently limited due to medicines being out of stock or simply unaffordable. At the same time, referrals to further treatment and operations are rare and delayed.

In Rhino Camp, there is also widespread drug shortage. The availability of a number of essential medicines and supplies has been affected, including antibiotics, drugs for managing non-communicable diseases, diagnostic supplies and equipment, and nutrition supplies (IRC 2025). Some essential drugs, such as insulin, are only available far from the settlement. Transportation is expensive, costing approximately 30,000 UGX in total, making it inaccessible to many. In general, the medicine available in the health centres is reported by patients to be very basic, and patients must buy medicine elsewhere, unless they can afford to travel the distance to the health centre in Rhino Camp town. Some specific medicines that are free by law cannot be purchased privately, such as antiretrovirals (ARVs) for HIV patients, so when the stock is low due to supply chain issues, patients cannot do much to bridge the gap. For patients with diabetes, the care available at clinics is limited, both due to a lack of insulin and also because it is no longer possible to measure the glucose levels, according to staff at the health centre. The only support offered by health professionals is advice on the recommended diet, which brings many patients into a dilemma as they cannot afford the recommended diet. Martha, a woman who suffers from several chronic conditions in addition to diabetes, describes:

> *"I am not able to guard it [diabetes] well because all the foods we have are oily, [and it is] bad. It's just up to you to think for yourself with diabetes. It does not like salt, it does not like something like oil or fat, it does not like that you eat and time passes [without eating again]."*

At the same time, Martha is also the sole caregiver of her five grandchildren. Even though the household receives cash support from the WFP, it is not enough to sustain their lives. The conditions in the camp make it close to impossible to live and eat in a way that keeps diabetes and other chronic conditions under control. Frequent meals of the right kind are simply not available for most households affected by chronic conditions, as they are also food-insecure.

4.4. Care shifts

The shifts in the funding landscape described in the previous section do not solely challenge the institutional care relations in the camps. Shifts in the funding landscape have implications for all three spheres of care relations – familial, sociable, and institutional – and lead to shifts in these care arrangements.

At the level of familial care relations, our findings point towards a shift in caregiving roles, where even children may be required to assume caregiving responsibilities in households affected by chronic disabling conditions. This could be partly due to funding reductions that affect the institutional care available. As medicine and treatment become inaccessible, the health of those with chronic disabling conditions may worsen, while the phasing out of the food assistance also results in adult caregivers needing to prioritise income-generating activities and sometimes relocate to look for livelihood opportunities, leaving children with increased caregiving responsibilities. This was the case for Sarah and her family, who left their elderly, ill mother and her son with Down syndrome in the care of young cousins who themselves were school-age. Lack of institutional care generally increases the need for – and dependence on – sociable and familial care relations.

The increased mobility of affected households also, in part, appears to be caused by the shifts in the funding landscape, which have led to reduced food assistance and health care. When medicine and treatment are not available or accessible, one also experiences a bodily care shift as physical or mental health deteriorates, such as the case of Paul, who has not been able to treat his kidney disease. For many, this shift in physical or mental health forces them to relocate to seek treatment or care outside the camps.

This increased mobility is not only physically and economically draining – it also challenges sociable care relations, which are crucial for households affected by chronic disabling conditions. In the camps, refugees recognise each other as 'community members'. Yet it takes time to establish one's status as a 'community member' and to create a social network. Sociable care relations depend on ties developed over time with neighbours, community groups, churches, and other community members. As we have shown, it is crucial for those with chronic disabling conditions that they are known and recognised by community members who respond to the needs of affected households. The situation is difficult for new arrivals who have not yet developed these ties. Similarly, you also lose the status as a community member once you shift to a different location in other camps or urban areas. Although many move to or with relatives or tribe/clan members, they still lose the wider network of the camp and have to rebuild their social network. The case of Juol, who has Down syndrome, would always be walked back home if he got lost in Rhino Camp, but when he got lost in Juba after relocating there, he was fortunate that a former community member from Rhino Camp recognised him and offered to help. Similarly, Rose, the elderly woman suffering from diabetes, decided to move back to Rhino Camp after discovering that Juba lacked the social care she had received in the camp where neighbours would visit and check up on her frequently. In the end, the sociable care by community members in the camp was more important for her.

Child with a chronic disabling condition sitting in a compound in a Ugandan refugee settlement @ Ayo Degett/DRC

5. Care relations under increasing pressure

In its first year, ADAPT has documented refugee efforts to care for chronic disabling conditions as humanitarian aid is rapidly shrinking. On the understanding that care is always a social relationship, we have examined three general kinds of care relationships and their interconnections. The cutbacks to resources for institutional care, particularly food assistance, are fateful for households that are already struggling for a livelihood. Likewise, the shrinking of resources for healthcare affects these households disproportionately. Institutions such as the RWC, staffed by refugees, are less able to assist because their members are also affected by the decline in humanitarian aid and must struggle more to support their own families.

In this situation, people are becoming more dependent on familial and sociable care relations. Trying to ensure some income to buy food and cover medical costs, not to mention school fees, is crucial. There are limits to the livelihood activities that 'disabled households' can undertake, and options are somewhat different in the three research locations. But familial relations are adjusting as best they can. For some, leaving is the best possibility. Many return to South Sudan despite the dangers; one member may leave to work in Juba and send money to others remaining in the camps. Bringing an infirm refugee to town for medical care requires support from a family member with resources, including a place to live.

Sociable relations of care continue to be important, although they are less regular than familial care. The ad hoc interventions of support offered in a critical situation can be lifesaving. In the longer term, efforts at "affirmative action" within local arrangements and semi-formal organizations are beneficial because they are more regular. Making positive exceptions for individuals and households with chronic disabling conditions gives them a small advantage that helps compensate for their vulnerability. We saw that in the case of the livestock-herding collective that provided milk, as well as in some VSLA and church groups.

With far fewer resources available in the aid sector, and with 2026 projected to see even further declines, the effects will soon become even more visible in the health and living conditions of vulnerable families in the research locations. Through an improved understanding of how care relations unfold and are practiced in this extended hardship, we aim to make the opportunities to improve conditions for care more visible. In the second year of ADAPT, while continuing to collect data, we will focus more on these opportunities. Bringing attention - and funding – to these options would require redefining how to best channel support to people with disabling chronic conditions, under a new and severely restrained funding environment. Final recommendations based on these opportunities will be co-developed with the community itself and representatives of implementing actors, policymakers, and donors to ensure they are realistic in terms of the funding available and relevant to the actual struggles people are facing.

5.1. Feedback and suggestions for the next stage

The findings in this report have been presented to the ADAPT Academic reference group as well as the refugee reference groups – along with the broader PARTOCA refugee reference groups – in Rhino Camp and in Kakuma and Kalobeyei for their feedback, recommendations, and suggestions. Through these consultations, we have included academic and community stakeholders' views on the questions we are addressing and the topics that would be relevant and necessary to explore in the next stage of the research. In addition, these consultation meetings provide an opportunity for the communities to inform us whether contextual aspects have been misrepresented or whether important nuances have been unintentionally omitted from the report. The meetings ensure that we can incorporate the views and feedback of community stakeholders, including members who are caregivers, health professionals, or living with chronic disabling conditions.

Overall, the findings, including the examples from the field and the contextual descriptions, were recognised and validated by the refugee reference groups in both locations. The members confirmed that the heavy reduction in food and cash assistance has negatively affected households with chronic disabling conditions, who previously benefited from this support. During the consultations, community stakeholders highlighted the current pressing issues for people with chronic disabling conditions, including limited transport facilitation to collect medicines or access health care facilities, a lack of support for suitable livelihood opportunities, and the consequences of funding cuts.

Multiple ideas for livelihood support were brought up; for instance, in Uganda, supporting farming initiatives, especially with tractors and seeds, was highlighted. In both locations, it was suggested that vulnerable individuals/households could be supported with starting a business, as explained by a person working in an RLO, who said, "*people [in] the community, they have different ways of survival. However, they're also skilful, knowledgeable and then innovative. Me, I'm looking in the angle of, if they could be supported with seed grants or seed funding such that they can build on their innovations, you know we have people who have innovations that are at the end, they earn a living out of it*". Similarly, although some livelihood activities may be too demanding for vulnerable households, it was highlighted that most would be able to rear chickens. In line with this, one member who is a prominent local representative of people with disability emphasised the importance of looking into the individual capacities of people with chronic disabling conditions and finding out how they can best be supported:

> "*The best way to support the vulnerable in the community, you know, we have a different category of people with disability or vulnerable people. So, there are some, we can be supported with the business [for] example retailer business. Others can be supported by training with skill training business depending on the category of the vulnerability. Why did I say that? Because if you collect them together, there may be a blind person, there may be a physical [disability], there may be deaf. They are different people, and they need to eat. All of them they are people who need to eat something (…) Like me, now I'm a person with a disability, but I have my eyes, I have my hand. I can do some other thing. But there's a person who is blind, can also do different thing*".

Members also emphasized that many households were phased out of the food support with no warning, and that in the future it would be better to support households with livelihood opportunities before moving them to category 3 or 4.

Lastly, several members of the refugee reference groups also stressed the increased importance of supporting community structures in the face of aid reductions, as highlighted by a member of an RLO:

> *"The humanitarian space has shifted from its traditional way of international organisation implementing into [a] new way of empowering local entities. And why are they doing that? Because we are focusing on the issue of sustainability. (…) What happens when there are no more funding? So, the informal community setup (…) these people need to be trained, need to be empowered with the little resources [available] because they understand the complexity of the community, they will be able to deliver even though international organisations have moved out. Because they have been there before the international organisations and they will be there after them".*

In line with this point, several members of the refugee reference group stressed the importance of involving refugee leaders in decisions on how best to prioritise funding, particularly the prioritisation approach, as they know the community's needs at large and the needs and capabilities of each household.

5.1.1. Future focus

Several additional topics that require further exploration have emerged from the data analysis and from feedback sessions with refugee communities and academics. The academic reference group members found it interesting and relevant to further examine the shifts in care resulting from changes in the funding landscape. Especially the changing caregiver roles in families affected by chronic disabling conditions, including the increased responsibility of children. Similarly, familial care has gendered expectations that could be explored further. Mobility has emerged as an important theme in this year's report, as individuals and households affected by chronic disabling conditions often need to move for various reasons: to access health care, to seek livelihood opportunities, or to be close to familial care providers. Among the academic advisors, it was suggested that we could dive deeper into the consequences of these mobility patterns for the sociable care many depend on. The following questions were raised: how do frequent movements between locations affect one's social network? How long does it take to build new social networks, which can provide sociable care? In relation to sociable care, members suggested exploring these dynamics further with a focus on community-level competencies and characteristics supporting those with chronic disabling conditions and how these competencies can be strengthened.

Man with a visual impairment in a Kenyan refugee settlement @ Ayo Degett/DRC

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Abbreviations

ADAPT	Adapting Humanitarian Response to Refugees' Endeavours: Managing Food and Health Insecurity
ARVs	Antiretrovirals
CHP	Community Health Promoter
CP	Cerebral palsy
CRRF	Comprehensive Refugee Response Framework
DR Congo	Democratic Republic of the Congo
DRC	Danish Refugee Council
DRS	Department of Refugee Services
GCR	Global Compact on Refugees
HCs	Health Centres
HIV/AIDS	Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome
ICF	International Classification of Functioning, Disability and Health
IDP	Internally Displaced People
IGA	Income Generating Activity
INGO	International Non-governmental Organisation
CBO	Community Based Organisation
IRC	International Rescue Committee
KES	Kenyan Shillings
KIIs	Key Informants Interviews
KISEDP	Kalobeyei Integrated Socio-Economic Development Plan
MFB	Minimum Food Basket
MoH	Ministry of Health
NGO	Non-governmental Organisation
NNF	Novo Nordisk Foundation
NRG	The NGO Refugee Group
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPM	Office of the Prime Minister
PARTOCA	Participatory Research Team on Community-Led Action
POC	Protection of Civilians camps
PSN	Persons with Specific Needs
PTSD	Post Traumatic Stress Disorder
rCSI	Reduced Food Coping Strategy Index
REF	Research and Evidence Facility
RLO	Refugee Led Organisation
RWCs	Refugee Welfare Councils
TB	Tuberculosis
UCPH	University of Copenhagen
UGX	Ugandan Shillings
UNHCR	United Nations High Council for Refugees
USAID	United States Agency for International Development
USD	US Dollar
VHT	Village Health Teams
VSLA	Village Loans Association
WBG	World Bank Group
WFP	World Food Programme

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