AFRICA-EUROPE GROUP FOR INTERDISCIPLINARY STUDIES

DISABILITY AND AID

An Ethnography of Logics and Practices of Distribution in a Ugandan Refugee Camp

Maria-Theres Schuler

BRILL

Disability and Aid

Africa-Europe Group for Interdisciplinary Studies

Series Editors

Gregor Dobler (*University of Freiburg, Germany*)
Manuel João Ramos (*ISCTE – University Institute of Lisbon*)

VOLUME 32

The titles published in this series are listed at *brill.com/agis*

Disability and Aid

An Ethnography of Logics and Practices of Distribution in a Ugandan Refugee Camp

By

Maria-Theres Schuler

BRILL

LEIDEN | BOSTON

This is an open access title distributed under the terms of the CC BY-NC 4.0 license, which permits any non-commercial use, distribution, and reproduction in any medium, provided no alterations are made and the original author(s) and source are credited. Further information and the complete license text can be found at https://creativecommons.org/licenses/by-nc/4.0/

The terms of the CC license apply only to the original material. The use of material from other sources (indicated by a reference) such as diagrams, illustrations, photos and text samples may require further permission from the respective copyright holder.

The open access publication of this book has been published with the support of the Swiss National Science Foundation.

Cover illustration: A woman with a walking disability leans on her cane as she walks across a field in the Kyangwali refugee settlement. Photo by Maria-Theres Schuler, Kyangwali, Uganda, August 2015.

The Library of Congress Cataloging-in-Publication Data is available online at https://catalog.loc.gov

Typeface for the Latin, Greek, and Cyrillic scripts: "Brill". See and download: brill.com/brill-typeface.

ISSN 1574-6925
ISBN 978-90-04-68301-3 (paperback)
ISBN 978-90-04-68302-0 (e-book)
DOI 10.1163/9789004683020

Copyright 2024 by Maria-Theres Schuler. Published by Koninklijke Brill NV, Leiden, The Netherlands.
Koninklijke Brill NV incorporates the imprints Brill, Brill Nijhoff, Brill Schöningh, Brill Fink, Brill mentis, Brill Wageningen Academic, Vandenhoeck & Ruprecht, Böhlau and V&R unipress.
All rights reserved. No part of this publication may be reproduced, translated, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without prior written permission from the publisher.

This book is printed on acid-free paper and produced in a sustainable manner.

Contents

PART 1

PART 2

PART 3

Preface

In 2010, Gitte Beckmann, Mareile Flitsch, Herbert Muyinda and David Kyaddondo from Makerere University in Kampala, Uganda, initiated the Disability and Technology research project, a long-term interdisciplinary cooperation between the Ethnographic Museum of the University of Zurich and the Child Health and Development Centre at Makerere University in Kampala. I count myself lucky that I had the chance to produce this book within the framework of the research project. Our research project had an applied component, which allowed me to stay in Uganda for two years – not only for research and scientific exchange, but also as part of several teaching and knowledge transfer events. The book is the result of a PhD study I pursued with funding from the Swiss National Science Foundation (SNSF) within the Disability and Technology research project, as well as through a one-year scholarship at the University of Copenhagen's Anthropology Department. The thesis was supervised by Mareile Flitsch at the University of Zurich and Susan Reynolds Whyte of the University of Copenhagen, and was awarded the 2019 Research Prize for excellence in policy relevant research on developing countries by the German Association's Research Group on Development Economics, and the 2020 Mercator Awards from the University of Zurich in the 'humanities and social sciences' category.

Acknowledgements

First of all I would like to express my thanks to Gitte Beckmann. Together with Mareile Flitsch, Herbert Muyinda and David Kyaddondo, she initiated the Disability and Technology research project and coordinated long-term cooperation between the Ethnographic Museum of the University of Zurich and the Child Health and Development Centre at Makerere University in Kampala, Uganda. I count myself lucky that I had the chance to produce this book within the framework of this research project. Gitte Beckmann not only introduced me to fieldwork in Uganda for my Master's thesis, but was also a wonderful mentor and friend during my PhD studies, always ready with the best advice at the right moment.

I owe my profound gratitude to my supervisors. Mareile Flitsch had already given me the best possible conditions to pursue this research before the project even began. I am grateful for all the opportunities that enabled me to realize this research, and for her valuable guidance all along. I thank my co-supervisor Susan Reynolds Whyte for the crucial questions she asked and the advice she offered during many conversations, for maybe unconsciously reminding me time and time again how great anthropology is, and for being such a wonderful host, together with Michael Whyte, during my stay at the University of Copenhagen.

Whilst researching I was part of several supportive and academic environments. I thank ISEK, the Social and Cultural Anthropology Department at the University of Zurich, for providing such a great working environment, and for giving me the opportunity to share and gain knowledge by various teaching opportunities throughout my PhD years. Esther Leeman's dedicated coaching support was especially invaluable. I am grateful to the Department of Anthropology at the University of Copenhagen for hosting me for a full year, during which I advanced my research project immensely. My special thanks goes to the head of the department, Helle Samuelsen, as well as Vicky Antosz for her help with all the paperwork and practicalities in Denmark. I am also thankful to the Child Health and Development Centre at Makerere University for providing me with an academic working environment for two years. I owe my special thanks to Anne Katahoire, director of the centre, and Augustine Mutumba for various administrative support.

In all these academic environments I was surrounded by amazing colleagues, many of whom have commented on drafts, presentations or papers that I have produced during this research project. They also gave me incredible emotional support during hard times, and shared invaluable tips and tricks for mastering a dissertation project. I am glad to have been part of a writing

group together with Rehema Bavuma, Lena Kaufmann and Francesca Rickli. Our monthly meetings provided much needed insight and support. I also want to thank a number of wonderful anthropologists who read through parts of my work and were crucial deadline keepers at the final stage of this project: Gitte Beckmann, Angela Birrer, Michele Dick, Molly Fitzgerald, Gabriela Hertig, Clemence Jullien, Daniela Lazoroska, Marc Meyer and Andrea Verdasco. Your feedback was an important source of encouragement at very critical points in time. I also thank Helen Rana for proofreading and editing my book in such a professional way.

During my fieldwork in the Kyangwali refugee settlement I experienced support in various ways. My heartfelt thanks go to Amani Bakunda, who helped me accomplish this research project – not just through his translation services. He helped me by enabling and ensuring access and rapport through his respectful and light-hearted way of interaction, and was a good friend and advisor for important decisions. I also thank Emma Ssempiira, the manager of St. Patricks Guesthouse, for providing me with such a warm home during my fieldwork. I would like to acknowledge Donald Mahanga, who officially taught me Kiswahili but actually tutored me in many other things regarding life in Kyangwali and life more broadly. For the transcription and translation work of my recorded interviews I thank Rehema Bavuma.

The research project was only possible due to generous support from several institutions. I most of all thank the Swiss National Science Foundation (SNSF) for funding my three-year PhD position within the Disability and Technology research project. The SNSF also funded my one-year scholarship at the University of Copenhagen through their doc.mobility programme and the open access publication of this book. North-South Cooperation at The Office of International Relations, as well as the Ethnographic Museum at the University of Zurich funded many further activities that took place around this research project. They supported our research group's regular meetings, as well as a field school in Uganda that I was able to organize along with Raphel Schwere and Francesca Rickli in summer 2017. I am grateful to the students of this field school for their interest in our research field and for co-creating such a friendly atmosphere for knowledge exchange. I also thank the participants in our Stakeholders' Dialogues on Disability and Research, held in Kampala. The critical and application-oriented inquiries and inputs from representatives of various international and national NGOs and disability organizations, as well as from the government, made me reflect on my research project in important ways.

I am very grateful to the School of Health at the College of Health Sciences, Makerere University, and the Uganda National Council for Science and Technology, for validating my research project and providing me with the necessary research permits to carry out this project. I also cordially thank the Office of the Prime Minister of the Government of Uganda for allowing me to conduct my ethnographic fieldwork in Kyangwali. My gratitude goes to the UNHCR Uganda, who not only acknowledged my research proposal, but also invited me to discuss my proposal and research results on several occasions.

This research project was also sustained by the support of my family and friends in Switzerland, Uganda and Denmark. I am so thankful for your continuous interest, for the visits to all the places this research project took me, and for providing me with a home away from home. I thank my various roommates in the different places for making me feel so welcome and for creating great working environments. I especially thank my Mum and Dad and my brothers for always believing in me without a doubt and for giving me all the support I needed to complete this project. My heartfelt thanks go to Francesca Rickli, who has been a great friend, critical voice and source of immense support throughout this project. I am so glad I was able to make this PhD journey together with you, although we lived on different continents for most of the time. Rehema Bavuma became a very close friend during this journey as well. I thank you for the shared joys and worries and the many office hours we spent together.

My greatest thanks go to all the interlocutors who took part in my study. I express my gratitude to the aid workers for their expertise and knowledge, and I thank the various aid agencies in Kyangwali for giving me a hand in finding answers to my questions. I am, however, most of all grateful to all the people with disabilities in Kyangwali and their families who so kindly let me participate in their daily lives, and who shared their knowledge and opinions with me. This study was only possible due to the many hours they spent with me, and their openness towards my queries and interests.

Glossary of Locally Used Terms

e	English (Ugandan)
k	Kinyabwisha
l	Luganda
s	Swahili

airtime (*e*)	top-up for mobile phone services
mtishobwoye/batishobwoye (*k*)	‘vulnerable’ person
boda boda (*l*)	motorbike taxi, a Ugandan rendering of the word ‘border’
chapati (*l*)	Indian-type flatbread
greens (*e*)	various types of green leafy vegetables
kajoriti (*s*)	disabled person; a Swahili rendering of the word ‘casualty’
kanzu (*s*)	long white robe worn by Muslim men in East Africa
kavera (*l*)	plastic sachet or polythene bag
kitenge/vitenge (*s*)	fabric with colourful prints
kuongeza (*s*)	to add
mandazi (*s*)	snack of sweet fried bread
matooke (*l*)	green bananas, also called plantains
mboga (*s*)	cassava leaves; also general expression for vegetables
msaada/misaada (*s*)	support, help, assistance
mzee/wazee (*s*)	old man; also a respectful way of addressing older men
obushera (*k*)	sorghum porridge
pikipiki (*s*)	motorcycle
posho (*l*)	staple meal (porridge) made out of maize
rolex (*l*)	egg omelette rolled in a flatbread, popular Ugandan street food
shangazi (*s*)	aunt
ugali (*s*)	staple meal (porridge) made out of maize
kilema/vilema (*s*)	(physically) disabled person
kipofu/vipofu (*s*)	blind person
kiziwi/viziwi (*s*)	deaf person
kiongozi/viongozi (*s*)	leader, official

mkubwa/wakubwa (*s*)	leader, superior; literally 'big person'
mlemavu/walemavu (*s*)	(physically) disabled person
watu wasiojiweza (*s*)	'vulnerable' people; literally 'people who are not able'
mzazi/wazazi (*s*)	parent
mzungu/wazungu (*s*)	white person, European

Abbreviations

ADF	Allied Democratic Forces
AHM	Africa Help Mission
ART	Antiretroviral Therapy
AIDS	Acquired Immune Deficiency Syndrome
CNDP	Congrès national pour la défense du peuple (National Congress for the Defense of the People)
CSB	Corn Soy Blend
DAR	Development Assistance for Refugee Hosting Areas Strategy
DRC	Danish Refugee Council
EVI	Extremely Vulnerable Individual
FPR	Front Patriotique Rwandaise (Rwandan Patriotic Front)
GoU	Government of Uganda
HI	Handicap International
HIV	Human Immunodeficiency Virus
HRIT	Heightened Risk Identification Tool
ICRC	International Committee of the Red Cross
IDP	Internally Displaced Persons
IOM	International Organization for Migration
LRA	Lord’s Resistance Army
MSF	Médecins Sans Frontières (Doctors without Borders)
NGO	Non Governmental Organization
NRR	Nordic Refugee Relief
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPM	Office of the Prime Minister
PSN	Person with Specific Needs
PWD	Person with Disability
PLWD	Person Living with Disability
REC	Refugee Eligibility Committee
ReHope	Refugee and Host Population Empowerment
RIMS	Refugee Information Management Systems
RSD	Refugee Status Determination
RWC	Refugee Welfare Council
SRS	Self Reliance Strategy
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations International Children’s Emergency Fund
UNHCR	United Nations High Commissioner for Refugees

US	United States of America
USAID	United States Agency for International Development
VAM	Vulnerability Analysis Mapping
WASH	Water, Sanitation and Hygiene
WFP	World Food Programme
WRC	Women's Refugee Commission

CHAPTER 1

Introduction

1 Whose Event? An Unequal Encounter

One day in mid-April 2015, the Kyangwali refugee settlement hosted a special event. In the grounds of a primary school, people arrived one by one, some slowly while leaning heavily on crutches, others limping, supported by wooden or metal sticks. Camille[1] extended her left arm to greet me before she sat down on one of the green and white plastic chairs that were arranged under the festively decorated tents. She had lost her right arm in an arson attack in the Democratic Republic of Congo. Mugenzi stood on the seat of his tricycle[2] with both his amputated legs to gain a better view over the grounds where the event would take place.

The occasion was to celebrate the completion of a one-year aid project that aimed to improve access to water and sanitation for people with disabilities. The project also educated them in matters of hygiene, and promoted their participation, inclusion and empowerment more generally. A huge banner bearing Aid Global's[3] logo, the international non-governmental organization (NGO) that had carried out the aid project, was prominently hung up along the wall of one of the school buildings. Along with the disabled people,[4] a large number of aid workers from various NGOs operating in Kyangwali waited in chairs beneath the tents that protected them from the scorching sun. However, when the black Mercedes Benzes and the beige Land Rovers arrived, they had to make room for the invitees from the Ugandan government and international aid agencies, accompanied by journalists and cameramen, to be

---

[1] I use pseudonyms for all my interlocutors in this book.

[2] A three-wheeled vehicle with a hand-crank.

[3] I use pseudonyms for all aid organizations operating in Kyangwali except for the United Nations High Commissioner for Refugees (UNHCR) and the World Food Programme (WFP). This is partly to protect the anonymity of the staff, but also because the organizations discussed in this book represent many others.

[4] I use the terms 'disabled people' and 'people with disabilities' interchangeably. The use of the 'people-first language' (i.e. people with disabilities) emphasizes that disability is not a person's main signifier. The 'disability-first language' (i.e. disabled people) complicates this stance. Promoters of this terminology argue that the 'people-first language' inherently assumes that disability is something negative and advocate that disability should be celebrated as diversity or shared identity instead (see Mackelprang and Salsgiver 2016).

DOI:10.1163/9789004683020_002

seated in the front rows. The festivity's programme included the guests visiting schools and households, a show by the 'Inclusive Drama Group', a performance by a locally-known musician with a disability and several speeches. As is usual at such events in Uganda, the official start of the programme was delayed for several hours until the guest of honour arrived.

The event's format and procedure – the speeches, the guests, the waiting and the cameras – signified that the project had been a success. A professional film crew went around capturing beneficiaries of the project for a promotional video and interviewed various stakeholders. A government official applauded Aid Global for acknowledging the plight of people with disabilities through national and international legislation towards their inclusion. His words on the project's impact were repeated in the glossy, photograph-filled brochure that was published after the event: "They [people with disabilities] are now recognized, respected as full and equal members of society, with increased self-esteem and reduced dependence on other people."[5]

It was particularly after this occasion that I started to wonder whether everybody involved in the project would consider it such a success. For people with disabilities and their families, this event was the last in a series of activities that were organized especially for them, and it bore quite a different meaning. "We felt sad that they [Aid Global] were leaving us," Mugenzi, the man with two amputated legs, told me in retrospect. He explained to me at that point:

> They [Aid Global] helped us a lot, and if they were still here, maybe they could have been helping us with more good things. They helped us with water, and I think they would be giving us more of those soaps that we are missing. They said that they were going to give us goats as well, but they left before that project was put into action.

I started the main phase of my ethnographic research in Kyangwali just a couple of days before this celebratory event, but I had come in contact with Aid Global's project when I visited Kyangwali on earlier occasions the previous year. Initially, the disabled people I interacted with had appreciated the intense attention and special assistance given by Aid Global. They perceived the project as very generous in comparison to what other aid organizations in Kyangwali had to offer. Over the course of my engagement with them throughout

---

[5] Aid Global, project brochure, handed out in Kyangwali in July 2015.

12 months of fieldwork, however, their tone towards the project changed. While people with disabilities had placed great hope in the project, many of their expectations were eventually disappointed: the project was limited not only in time, but also in the kind of assistance it provided.

These different feelings of hope, possibility and disappointment that evolved around Aid Global's project exemplify disabled people's experiences with the aid system more generally. Yet, rather than simply being a result of the limitations of Aid Global's project, I will argue in this book that disabled people's experiences with the aid system stemmed from an encounter of the different logics and practices of distribution at play in Kyangwali. By logics of distribution, I mean the principles upon which a person was deemed entitled to assistance and resources, and could claim them. Importantly, while the aid agencies had an explicit discourse about their logics in written guidelines, policies, and procedures, this was not the case for the refugees. This book is therefore equally concerned with practices of distribution, expressed both in actions and words.

Logics and practices of distribution shaped the relationships between aid agencies and their beneficiaries, disabled people, in manifold ways: through humanitarian assistance categories that defined and channelled access to aid, or through the ways disabled people understood their own position in the social fabric of the aid system, its organizations and their staff. In examining these different logics and practices, it became exceedingly obvious that aid agencies' assumptions about who should be entitled to what support, based on which principles, often did not align with refugees' perceptions and expectations, and thus often failed to fit their realities.

2 Disability as a Distributive Category

Disability can be defined in terms of ideas and values about distribution. So argues political scientist Deborah Stone in her seminal book *The Disabled State* (1986), in which she shows how disability as a category determines who is entitled to social aid. With the emergence of the disability category within welfare states' distributive mechanisms, certain kinds of people – formerly targeted as the infirm, invalids, lunatics or defectives – have been assigned a social and political identity, either as one of a group, or as individual citizens. The relationship between disabled people and the global aid regime was constituted similarly to that between states and citizens: my interlocutors in Kyangwali were also entitled to special assistance, which they could claim from an authority – in their case a supranational organization, the United Nations High Commissioner for Refugees (UNHCR).[6]

When I inquired about disabled people during my first encounters with aid workers in Uganda, they immediately referred to the humanitarian assistance category 'PSN', which stands for 'person with specific needs'. They also pointed out that this category had to be distinguished from the 'EVI' category, which stood for 'extremely vulnerable individuals' and may or may not include people with disabilities. Disability thus worked as a distributive category within a larger standard set of hierarchically ordered categories and sub-categories that aimed at distributing scarce resources in the most fair and effective way possible. Like people with disabilities, orphans, elderly people, single mothers or those with chronic medical conditions were also categorized as being vulnerable, due to their assumed physical, economic or social disadvantages.

In Kyangwali, as in every other context in which it operates, the UNHCR's approach to 'vulnerable' people[7] was guided by the UNHCR booklet *Guidance on the Use of Standardized Specific Needs Codes*, which informed about the use of the PSN category. It divided the category 'Disability' (coded DS) into the sub-categories physical, mental, intellectual, or sensory impairments and disabilities. These sub-categories were further divided into 'moderate' and 'severe'. As universal codes, they were used to manually and biometrically register refugees upon their arrival, but also in ongoing needs assessments. The EVI category that designated 'extremely vulnerable individuals' was used to indicate priority eligibility for any kind of support. In Uganda's refugee context it was especially relevant regarding food aid.

The categorization approach to vulnerability was implemented worldwide through the working procedures of the UNHCR and its partners, the various humanitarian organizations active in a particular refugee context. By

---

[6] Several scholars have challenged existing conceptions of national citizenship in line with the globalization process. They argue that current forms of citizenship do not necessarily match territorial configurations, and that people are increasingly protected by, and entitled to support through, transnational institutions and international human rights frameworks (e.g. Eckert 2011; Feldman 2012; Ong 1999; Rose and Novas 2008). They show how practices of legal recognition and claim-making have emerged in institutions and social arrangements beyond the state, be it in refugee camps (Inhetveen 2010) or in global health projects (Biehl 2004; Nguyen 2008).

[7] Throughout this book, I will put the word 'vulnerable' in quotations, when used as an adjective for people – assuming that it is certain situations and conditions that render people vulnerable, not that certain groups of people are vulnerable per se. However, this does not exclude a perspective that human life as such is something inherently vulnerable, as discussed, for example, by philosophers Martha Nussbaum (2009) and Martha Fineman (2008).

establishing norms and standards which seem to be objective, there is a risk that these categories exist unquestioned, although they are by no means unbiased. Given the immense range of the UNHCR's categorization approach – in 2015 the agency employed more than 9,300 staff in over 125 countries, assisting 42.9 million refugees and other people of concern (Sandvik and Jacobsen 2016, 1) – the absence of any discussion of these categories and their assessment criteria is particularly astonishing.

A focus on these categories is important because they impact on matters of distribution and personhood, and because aid workers and aid recipients alike deal with them on an everyday basis: for assessing and registering information about people, for programme planning, reporting and accounting, as well as for allocating aid and services like hut construction or resettlement to a third country. In contrast to the detailed documentation on the inclusion and exclusion criteria of the PSN or EVI categories, there was almost no written guidance on the entitlements that resulted from these categories. The entitlements were subject to constant changes in funding and funding priorities, yet they determined a refugee's opportunities to access aid immensely.

Very early on in my fieldwork in Kyangwali I observed for myself that disability could be a desired category. When I made my way around Kyangwali, I was frequently approached by strangers pointing to a scar, a slightly malformed finger, or putting their hands on their hips to emphasize their claims that "I'm also a person with a disability!" As humanitarian aid was present in the Eastern Democratic Republic of Congo, where most of my interlocutors had fled to Uganda from, residents in Kyangwali were well aware that people with lost limbs, deformed legs or back injuries were perceived as vulnerable by the aid agencies and therefore qualified for special support. As they knew about the potential advantages of being categorized as disabled, it was unsurprising how many of them identified themselves or someone they knew and cared about as such. Disability was thus an important and contested category in Kyangwali, the definition of which was constantly being negotiated by affected people and aid organizations alike.

The distribution of aid or assistance of any kind by the means of categories always requires applying objective criteria to define how deserving an applicant is. Social scientists have demonstrated how these criteria for disability are grounded on assumptions about inability and dependence, which are above all medically defined and based on the individual body (see e.g. Ingstad and Whyte 1995; Kohrman 2003; Petryna 2013; Stone 1986). This book further explores how people with disabilities were considered and categorized as being in need of assistance, and what kind of aid this entitlement entailed. However, it considers these questions in an institutional and social context, where inability and dependence were not only defined differently, but also carried a distinct meaning.

3 Different Logics of Distribution

In welfare states, the basic principle of distribution is work (Stone 1986, 15). State-based social security systems target citizens who are unable to work, such as the elderly, the disabled, or those caring for children, as being entitled to claim social benefits. The concept of disability became especially relevant in this development during industrialization, and capitalism rendered people with disabilities into the category of those being eligibly dependent (Oliver 1990). In a society where each individual is responsible for fulfilling his or her needs by working and earning, the disability category functions as a boundary device to define the line between the 'normal' state of work and social benefits (Stone 1986, 21).

The centrality of work for distribution says something about personhood and ideas of dependency in the global North more broadly. People are ideally expected to be independent through work, instead of being dependent on social aid. Thus, the notion of independence, as inscribed in disability through its absence, is at the core of a Western individualized understanding of body and personhood (Devlieger 2023, 7; Ingstad and Whyte 1995, 11). Moreover, values of equal opportunity derive from a Western ideal that Ingstad and Whyte have called a 'desirability of equality'. For people with disabilities, this ideal became important after the First World War in Europe when, in order to care for the war wounded, rehabilitation emerged as the response to restore a previous, assumed 'normal' condition, and special entitlements were given to support people who had difficulty competing within the labour market (Ingstad and Whyte 1995, 7–8). Although these understandings of disability and broader ideas of personhood and distribution are anchored in very specific historic and cultural backgrounds, they travel in definitions, criteria and standards that are seemingly universal (Ingstad and Whyte 2007, 2). They came into contact with disabled people in Kyangwali through the humanitarian assistance categories, as well as disability programmes.

In geographical settings where possibilities for formal employment or social security through welfare institutions are largely absent, distribution works differently. In his book *Give a Man a Fish* (2015), James Ferguson leads us through distributive practices within the pre-colonial Ngoni state, colonial and apartheid Southern Africa, ultimately drawing our attention to the ongoing importance of relations of patronage in contemporary South Africa. He shows how most people in that country today survive partly by making distributive claims on other people's income streams and wealth. I experienced the relevance of these relations, within which people who have more are supposed to support and protect those who have less, in my own position during my fieldwork in Kyangwali. As a white researcher with a certain connection to the service providers, some people addressed my research assistant and I with the words *wakubwa* (Swahili for 'big people'), *viongozi* (Swahili for 'leaders'), or *wazazi* (Swahili for 'parents'), which they also used for humanitarian and governmental staff, and often asked me for financial contributions or help to acquire things, for example, an assistive device from an aid agency.

Although not dealing with the issues of disability or displacement, Ferguson's work on the politics of distribution in southern Africa is of special importance to me, as he tries to differently value dependency in its respective contexts. He argues that people in southern Africa desire dependent relationships with powerful others because these allow them to make claims from their patrons (2015, 25). He introduces the concept of 'distributive labour' to demonstrate that the ability to make claims on other people's resources is the result of the "long and careful work [that] goes into building the sorts of social relationships that make such distributive flows possible" (97). This represents a radically different stance on dependency from that in the global North, where a predominant fear of dependence has derived from the Enlightenment paradigm that promoted individual freedom and equality. To position oneself as dependent, Ferguson argues, is perceived as the exact opposite of this developmental progress (143).

This also reveals how far dependency is perceived as something inherently negative within the humanitarian world. Anthropologists have critiqued humanitarian interventions along this line, by pointing out that they produce highly unequal relationships between displaced people and humanitarian agencies (Harrell-Bond 2002; Harrell-Bond et al. 1992; Malkki 1996; Müller 2013). In Kyangwali I observed that aid agencies saw the so-called 'dependency syndrome' – the fear that aid creates passivity and excessive demands (see Harrell-Bond 1986; Malkki 1992; Nabenyo 2019) – not only as problematic for the refugee population in general, but for disabled people in particular. An aid worker articulated this in an interesting way, when she evaluated Aid Global's project: "Sometimes the 'disability syndrome' is in the mind, so the more we bring them [people with disabilities] on board, the more the level of dependence will reduce".[8]

---

[8] Aid Global, project brochure, 2015.

Yet, the idea of such a 'dependency syndrome' has increasingly been debunked as a myth, most prominently by Gaim Kibreab (1993), who portrays refugees rather as being active, resourceful and creative under circumstances of extreme constraints (see also Bakewell 2003; Hyndman 2000). However, both perspectives perceive dependency as something negative, a situation that either needs to be altered through changing power relations, or something that should be countered by showing that, in fact, refugees are not (only) dependent, but also active participants in the creation of humanitarian interventions. Throughout this book I will adopt a different stance on the dependency of refugees with disabilities and thus provide a more nuanced picture of its assumed problems – a picture that is urgently needed to understand the manifold tensions and mutual lack of understanding between beneficiaries and aid agencies, evident in practically every humanitarian and development context. For this, it is relevant to recognize that, in Kyangwali, dependence was not an inherently negative thing, but a sort of deep logic that shaped the social fabric of the refugee settlement.

4 Uganda's Success Story: Promoting Self-Reliance

In 2017, Uganda became the largest refugee hosting country in Africa, when it reached the record number of 1.4 million refugees, mostly from South Sudan (1,037,400 refugees) and the Democratic Republic of Congo (226,200 refugees) (UNHCR 2017, 17). Uganda then not only hosted the third highest number of refugees worldwide (after Turkey and Pakistan), but had also adopted one of the most progressive refugee policies that existed in the world (Betts et al. 2017). "Is Uganda the Best Place to be a Refugee?", asked an article in The Guardian from 2016, reviewing the country's unusual open policy for refugees (Patton 2016). On several other occasions during the 'Refugees Welcome' campaign in Europe, Uganda featured in the Western media as an exemplar for its progressive refugee policies, particularly when considering what available resources an African state is assumed to have to host refugees (e.g. Givetash 2018; Thompson 2016; Urech 2017; Wülser 2016).

Uganda had become known for its unusual open refugee policy since the implementation of the Uganda Refugee Act in 2006 and the Refugee Regulation of 2010 (Givetash 2018; Patton 2018; Thompson 2016). It granted refugees rights to property, work, and movement, as well as access to public services including education.[9] Most crucially, it aimed to encourage refugees

---

[9] These rights are set out in the UN 1951 Convention and the 1976 Protocol in Relation to the Status of Refugees (Ramsay 2017, 85).

towards self-reliance and independence from aid deliveries by allocating them a plot of land in assigned settlement areas. The Government of Uganda had followed this aim of self-reliance by gradually integrating service structures for refugees into their national systems; first through the Self-Reliance Strategy (SRS) in 1999, and later as part of the UNHCR's broader global strategy of Development Assistance for Refugee Hosting Areas (DAR) and the Refugee and Host Population Empowerment Strategy (ReHope) (Ilcan et al. 2015; Meyer 2006; Svedberg 2014).[10]

The naming of these policies – self-reliance, development, empowerment – are telling in regard to this overall transition from emergency assistance to development-oriented refugee aid, which is a wider global phenomenon. Since the late 1980s, diverse actors have pursued the idea of self-reliance – not only in refugee camps, but also in development cooperation and the fight against poverty. In line with neoliberal values as a governing principle, various measures encouraged refugees to actively take on more responsibility to meet their basic needs in order to get by with as little humanitarian aid as possible (Ilcan et al. 2014, 1; Ramsay 2017, 85; Svedberg 2014, 12; see also Easton-Calabria and Herson 2020). Uganda's settlement approach ought to provide an enabling environment in which refugees can develop their capacities and – at least in theory – become economically independent. This was implemented in practice by allocating land to refugees in 14 assigned rural settlement areas, where they could carry out subsistence agriculture.[11] Refugees were initially given food rations and materials to build a home, and given access to basic health care and education – services which were not provided (for free) to refugees living outside the settlement areas.

The Kyangwali refugee settlement hosted around 40,000 people in 2016, mostly from the Democratic Republic of Congo, and was – like other refugee settlements in Uganda – not fenced, in order to facilitate entrepreneurial activities. The biggest of its 16 villages at the entrance to the settlement, Kasonga, offered a range of shops, restaurants and bars, and was home to hairdressing

---

[10] With the launch of the ReHope strategy in 2015, refugees were officially mentioned in Uganda's 'Second National Development Plan' (GoU 2015).

[11] The amount of land was allocated according to the size of a household on arrival: for both residence and agriculture, families of one to five people officially received a plot measuring 50 by 100 metres. Families of six to nine qualified for two plots, and bigger families for three plots (Norris 2013, 17; GoU 2014, 20). There were, however, significant changes in this land allocation over time, and the size of plots was repeatedly reduced or adjusted, depending on the number of refugees in the settlement at any particular moment. During the 2012 emergency, for example, when a large number of Congolese refugees arrived in Kyangwali, the plot sizes were reduced to 50 by 50 metres, and later on, residential land plots were again reduced to 20 by 30 metres (GoU 2014, 20).

salons, phone charging stations, a small market, several churches and a mobile money centre. Young men with *boda bodas*[12] were especially busy on the weekly market day in another village in the settlement, transporting merchants and clients along the mud roads in and out. However, the settlement was located in a remote rural region in Western Uganda, 80 kilometres from the next bigger urban centre. A small car squashed full of up to nine people usually made its way on the bumpy road from Hoima town twice a day. Public transport was also rare within the settlement: most people moved around by foot, some by bicycle, and a few could afford to use *boda bodas*.

The 147 square kilometres of land were allocated to host Rwandese refugees in the 1960s as they were sparsely populated (Adelman and Suhrke 1999, 10). After the majority of Rwandan refugees were repatriated from Uganda in 1994–1995, the settlement area was declared vacant until 1997, when Congolese refugees began arriving with the rise of the current crisis in Eastern Congo (Werker 2007, 463). During my fieldwork, the place did not look much different from other places in rural Uganda. Some of the homesteads with grass-thatched or iron-sheeted roofs, sometimes equipped with a solar panel, were of a more temporary nature though. The people's clothing could also be discerned as a difference. The traditional *kitenge*[13] dresses were much more common than elsewhere in Uganda, and a noticeably large number of people wore T-shirts bearing the logo of a humanitarian organization.

In theory, a clear distinction is made between refugee settlements and refugee camps: the latter does not provide access to land for farming or freedom of movement, and has a much denser population (see e.g. Schmidt 2003). In Kyangwali, the borders of the settlement were somewhat fluid. According to Uganda's Refugee and Host Population Empowerment Strategy (ReHope), 30 percent of the assistance that humanitarian organizations provide should reach the host community. Basic services like education and health facilities were meant to be also accessible for Ugandans.[14] Most of the Ugandans living in close proximity to the refugee settlement were of Batooro origin and thus spoke a Bantu language, which considerably eased communication between the refugees and their hosts. They interacted in various ways, for example as

---

[12] *Boda boda* is the Ugandan description for motorbike taxis. The term derives from the border areas where they were initially used, as the conductors shouted out 'border, border' to attract clients.

[13] *Kitenge* is the Swahili name for a widely-used, colourful printed fabric in East Africa. They are especially used to make women's dresses, but they are also used as wrappers, headscarfs, blankets or baby carrying cloths.

[14] Although the Congolese schooling system is based on French, once in Kyangwali, people received an English education according to the Ugandan curriculum.

both traders and buyers in the weekly market or by hiring labour to work on their fields. Some of my interlocutors sent their children to better schools outside the settlement or themselves attended a course, for example in computer skills, in a nearby town.

Although the borders were fluid, they did exist, and could mean barriers in certain circumstances (see Turner 2016, 141). Freedom of movement, for example, was not always as simple as it seemed. While not legally required, people in Kyangwali often waited for days to receive a 'movement permission' issued by the governmental camp authorities – a document that officially served as protection, for example during police inquiries. Some of the literature thus suggests that camps and settlements are essentially the same when it comes to the ways that people are organized and controlled (Hovil 2007; Kaiser 2008; Malkki 2012). Although humanitarian and governmental staff in Uganda reprimanded me vehemently when I used the word 'camp' – in their eyes erroneously – in this book I will use the terms settlement and camp interchangeably, acknowledging both the differences and similarities between these structures, and acknowledging the way that my interlocutors called it *campu* in Swahili.

The official authority in Uganda's refugee settlements was the Office of the Prime Minister, which houses the Directorate of Refugees. Referred to simply as OPM by refugees and humanitarian staff alike, their offices were situated right by the entrance to Kasonga, the settlement's largest village. A forest of signposts announced their presence and pointed towards the offices of the various UN agencies and NGOs operating in the settlement. The OPM's main activities were to determine refugee status and to allocate land to refugees, as well as to physically protect the refugee population, through the presence of the army and police. People who held a high military rank usually occupied the senior posts of settlement commandant or deputy settlement commandant in the OPM. People often queued up in front of the gate to the office compound while waiting to be issued with all sorts of documents – refugee attestation cards, food ration cards, or permits for travelling outside the settlement.

The UNHCR offices were much less accessible, their high new walls in gleaming white and blue surrounding their expansive compound, topped with barbed wire. The UNHCR's mandate in Kyangwali was to protect refugees in line with the UN Refugee Convention, and it coordinated and monitored diverse activities between the various implementing and operating partners in the camp. As the main donor, it decided which responsibilities and domains were awarded to which NGOs as implementing partners.[15] While not

---

[15] In contrast to implementing partners, operational partners are organizations which have their own funding, but are nevertheless under the UNHCR's supervision.

implementing the activities itself, it was the final decision-maker, not only with regard to allocating funds to various projects, but also in relation to individual benefits, for example whether a tricycle would be acquired for a person with a disability or not. Without having an appointment with one of the UN officers, a glimpse into their modern premises was only possible when the large gate opened and the white UN Land Cruisers with antennas brought the staff out 'to the field' – a term used in humanitarian speak to describe the situation when the well-dressed aid workers left their air-conditioned offices to conduct home visits, training sessions or assessments in the villages.

Not just the humanitarian assistance categories, but also the physical structure of the camp, the legal framework, as well as international policies served as practices and measures through which to implement Uganda's self-reliance strategy. In the Kyangwali refugee settlement, most people had fled from Eastern Congo between 1998 and 2014, leaving behind all their worldly goods, and often losing family and friends during violent conflict and displacement. In the remote area of Kyangwali on the shore of Lake Albert, they were given land to cultivate and build their new homestead on. I was intrigued to discover how people with bodily challenges were considered in this physical and institutional environment that clearly assumed able-bodiedness as its norm. The idea was that refugees should become self-reliant by farming the land allocated to them, while the aid agencies gradually scaled back their relief operation by reducing and eventually phasing out their food rations. People who struggled to use the land efficiently due to their health status, age, mobility or the number of dependents they had to care for were categorized as 'extremely vulnerable' and entitled to special food aid. It was against the background of the self-reliance strategy that my research interest fell on people with motor and mobility disabilities.

5 On the Humanitarian Agenda: A Paradigm Shift

In April 2015, when Aid Global's project ending event took place in the Kyangwali refugee settlement, paying special attention to disability among refugees was a rather recent development. The UNHCR had adopted the Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR in 2010 (UNHCR 2010), and published guidance on Working with Persons with Disabilities in Forced Displacement in 2011 (UNHCR 2011b). More recently, the Charter on Inclusion of Persons with Disabilities in Humanitarian Action was developed in advance of the World Humanitarian Summit in May 2016, and then ratified, aiming to reduce barriers for people with disabilities within the humanitarian context (UNHCR 2016a).

When I started engaging with refugees with disabilities, the notion of 'vulnerability' became a central term straight away. Policy researchers and aid agencies alike often portrayed disabled refugees as carrying a 'double vulnerability', being among "the most marginalized in an already disposed group" (Refugees International 2003, quoted in Karanja 2009; see also Reilly 2008; Smith-Khan et al. 2014). Yet, why has the concept of vulnerability become so important in humanitarian aid, and especially for people with disabilities?

When the UNHCR extended its original mandate – the borders of Europe and the 1951 Refugee Convention – its founding principle of legal protection was also transformed: from legal advice to humanitarian relief. With its expansion, the assistance itself became tailored more and more to specific groups of people. Historian Joël Glasman has examined this for the African Great Lakes region, arguing that the UNHCR's expansion demanded a specialization of its interventions and resource allocation (2015). Thus, categorizations became more important and the UNHCR increasingly prioritized refugees through a prism of needs relating to their level of vulnerability. In the 1980s and 1990s, experts in health, nutrition, education, shelter, and sanitation defined UNHCR's 'minimum standards' for assistance, and the basic needs of refugees became associated with immediate, life-saving services in emergency situations. People were thus classified not only according to their legal status, but also according to their – often bodily defined – vulnerability.

The concept of vulnerability is important for recognizing and protecting marginalized groups and individuals who are at risk. It evokes "the need to help" (Malkki 2015), and is therefore also important for aid organizations' fundraising activities. However, in recent years prior to my fieldwork there had been an important paradigm shift in how it was thought disabled people should be recognized as in need of attention and support, and how the aid agencies should best address their situation: while approaches on disability in humanitarian settings were long embedded in a medical and rehabilitative paradigm (Mirza 2011b, 1528–1529), attention had increasingly shifted to focus on issues of accessibility and human rights. It is no surprise that the initial focus on disability in humanitarian settings was individualized and medicalized: humanitarian approaches are typically embedded in principles of charity and draw on compassion as the rationale for intervention (Ticktin 2006, 34). With its overall imperative to reduce suffering and save lives, the humanitarian approach towards disability has thus centred on vulnerability in the individual person's body. Within a more holistic approach that focuses on human rights, however, vulnerability was becoming situated within social and environmental structures. This approach argues that people are not vulnerable per se, but are more or less vulnerable in specific situations and due to certain circumstances (Clark 2007; Clark-Kazak 2011; Epstein 2010).

How disability and its assumed vulnerability have been targeted differently within humanitarianism has been accompanied by a shift in scholarly attention on disability. Up until the 1970s, the medical sciences, psychology and pedagogies mainly perceived disability as an individual physical deficit or incapacity of bodily functions. Yet, when the social sciences and humanities started engaging with it, they understood disability not as an individual problem, but as a form of social exclusion that emerges through social and environmental barriers created by society (Oliver 1990; Shakespeare 2006; Thomas 2002). Attention towards disability within humanitarian practice under this social premise has been growing, especially since the introduction of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008. As with other international human rights instruments, all of which aim to ensure the universal equality of individuals, protection against unequal treatment or discrimination is at the heart of the UNCRPD (Mikuš 2018, 296). Rights are seen as an instrument to empower disabled people, in order to make them equal and independent.

Within humanitarian practice, the focus on rights presents disabled people as being capable and active, instead of viewing them as vulnerable and passive victims (Njelesani et al. 2014, 85). Consequently, rights-based approaches advocate creating equal opportunities and access for disabled people, and overcoming discrimination through advocacy, empowerment and participation, instead of merely providing emergency aid in the form of material assistance for basic needs with the idea of compensating for a bodily deficiency. This shift from charity to rights is relevant not only in relation to disabilities, but also within a broader sustainable development discourse, as in the Global Agenda 2030 (UN 2015), in which the ideals of inclusion and equality have a firm standing.

In a refugee policy context that starts from the premise of able-bodiedness, and at a time when disability is high on the humanitarian agenda, it is crucial to ask what it actually means to live as a refugee with a disability in Uganda. What is the significance of being categorized as disabled at this specific historical moment during a paradigm shift that places disability and its assumed vulnerability in a new light? This book diverges from the commonly-held view in much policy and other research that, when protracted refugee contexts intersect with disability, "the situation can be nothing short of toxic", as Maria Pisani and Shaun Grech write (2017, 431).[16] Rather than viewing intersections

---

[16] There is an expanding body of research that focuses on the hardships faced by refugees with disabilities and also, importantly, emphasizes vulnerability, barriers and discrimination against disabled people in displacement contexts (e.g. Couldrey and Herson 2010;

between disability and displacement as toxic per se, I analyze the social and institutional conditions that shaped disabled people's life in a refugee settlement and ascertain how they actually interplayed. An ethnographic study that thoroughly links the social and the institutional by focusing on categories and distribution in a refugee context is crucial, as it clearly shows how the various forms of aid and the assumptions on which they are based have a concrete impact on the opportunities of people with disabilities to cope with their lives.

6 When Aid Agencies Become Patrons

In addition to physical challenges or institutional blind spots, the aforementioned reports and literature consider disabled people to be vulnerable in displacement contexts due to the loss of important social relationships. They identify women, children and older people with disabilities as particularly vulnerable in such situations, being exposed to discrimination, exploitation and sexual and gender-based violence (e.g. Reilly 2008).[17] Violent conflict in Eastern Congo and displacement certainly had led to drastic ruptures in my interlocutors' social relations. They had lost or left behind family members, friends and neighbours. The large majority of disabled people I interacted with in Kyangwali were living with a spouse and their children. Yet, the network of extended kin had decidedly reduced, and no one I knew had a big circle of aunts, uncles or cousins nearby to draw on when in need of money for medicine or scholastic material, for example, or when seeking assistance for daily activities like child care, gardening or looking after a disabled or ill family member.

While social relations play important roles for everyone, they have significant implications for disabled people, compared to other refugees that often

---

Crock et al. 2012; 2017; HI 2015; Karanja 2009; Kett and Twigg 2007; Kett and van Ommeren 2009; Kett and Trani 2010; Mitchell and Karr 2014; Nagujja 2013; Reilly 2008).

[17] I have refrained from using vulnerability as an analytical concept, not only because it is used by the aid organizations themselves, and often indiscriminately, but also because the word itself has little relevance in local usage. There is no word in Swahili that equates to the term 'vulnerability' or 'vulnerable'. Disabled people as well as other refugees in Kyangwali used the expression *watu wasiojiweza* (Swahili for 'people who cannot help themselves') or the corresponding Kinyabwisha word *batishobwoye* to refer to 'vulnerable' people. These expressions were also translated by my research assistants as 'the helpless', 'the weak', 'the needy' or 'the unable'. Furthermore, the aid agencies' understanding of vulnerability had long considered certain groups and individuals as vulnerable per se (Bakewell 2008; Berghs 2015a; Clark 2007), and did not focus enough on the situations and conditions that render them vulnerable.

struggle with similar challenges (see also Muyinda 2008). The people who shared their stories with me had acquired their disabilities at different points in their lifetime and under various circumstances – be it through polio during childhood or an injury suffered in violent conflict. When learning how disabled people in Kyangwali went about their lives, what they strove for and what they struggled with on a daily basis, the role of the aid organizations was always present to some extent – not only physically through the various interventions and aid they delivered, but also in my conversations with disabled people.

In this book I argue that, in a way, the aid organizations became important providers through which claims could be made, support be secured and belonging negotiated as an alternative or an addition to people's social networks. An incident at the World Refugee Day celebration in Kyangwali in 2014 exemplified these patron-client relations between the aid organizations and my interlocutors. Like any other organization, Aid Global had distributed promotional T-shirts to some of their beneficiaries that day. One of their aid workers handed a T-shirt to a disabled woman, who instantly pulled it on over the top of a T-shirt she had previously received from another aid agency. Seemingly offended by this act, an aid worker from the first organization approached the former, arguing that this person "belonged to their organization" (see also Whyte et al. 2014, 56).

'Belonging to an organization' has parallels with longstanding discussions about the concept of patronage in the workings of African political systems, in which moral obligations and expectations are structured around vertical ties of personal interdependence (e.g. Fortes and Evans-Pritchard 1987; Miers and Kopytoff 1979; Vansina 1990). Africanist scholars emphasize that actors are both patrons and dependents within long hierarchical chains of support: patrons need to fulfil their clients' expectations to retain their reputation, while clients have to be loyal (Chabal and Daloz 1999). 'Wealth in people' (Miers and Kopytoff 1979) or 'having people' (Smith 2004) is what counts, because both clients and patrons provide access to opportunities and resources.

Social scientists have started drawing attention to how international NGOs and their representatives are increasingly taking on this role in societies where people are constantly looking for patrons and resources. Of particular interest is what clients do for their patrons in these relationships, such as providing information or being present when donors visit local NGO projects (Swidler 2009), or that aid in the form of charity seems to be more in line with the workings of patron-client relations than a form of aid that aligns with contemporary ideals of sustainable development (Scherz 2014). Building on these studies, in this book I look, on the one hand, at the interdependent relations between service providers and their own donors. On the other hand I inquire into how disabled people understood their relation to the aid agencies. Through this I reveal how aid initiatives interplayed with the distributive flows that took place within disabled people's various relationships in the refugee settlement.

Although a standardized categorization system with defined criteria guided the distribution of aid in Kyangwali, the interdependent relations between the beneficiaries, the service providers and their donors thoroughly shaped this seemingly transparent aid distribution. Access to aid was based not only on an applicant's categorization as a PSN or EVI, but also on the hierarchical chains of support between different service providers and the funds they had available, as well as donor prioritization. Whyte and Siu draw on the concept of contingency to think about the interplay of personal and impersonal dependencies, distinguishing between social and historical contingencies. By the latter, they mean the largely impersonal interdependent relationships with institutions that are themselves linked to, and dependent on, larger events (2015, 20). I too analyze people's dependence on changing donor priorities or political conditions in Kyangwali as being historically contingent – as processes on which people are ultimately dependent but have no chance to directly engage with through personal relationships.

Yet, access to aid was also thoroughly shaped by disabled people's personal contacts with the aid agency staff who administered categories, conducted interviews, and made assessments. Aid agencies also depended on the beneficiaries' cooperation – to follow the given procedures for aid distribution, to provide information and signatures and to be physically present – in order to keep the donor money flowing. It was particularly interesting in these interdependent relationships when disabled people expressed to aid workers their mistrust about the aid delivered – a very common situation – insisting on a certain morality of exchange, grounded in a logic of distribution in which they perceived the aid agencies as their patrons who also had to fulfill obligations towards the refugees. Especially as these agencies were powerful organizations that were obviously connected to a world of wealthy donors, disabled people felt that their initial and promising recognition as refugees did not materialize, leading to a pervasive and profound disappointment.

7 What it Means to Be a Beneficiary

Anthropologists have also analyzed the relation between people and aid programmes through notions of therapeutic (Nguyen 2008) or biomedical citizenship (Biehl 2004), showing how practices of legal recognition and claim-making have emerged in institutions and social arrangements around global health projects. When Whyte et al. (2014) studied access to antiretroviral therapy (ART) for people living with HIV/AIDS in Uganda in their book *Second Chances*, they developed the concept of 'clientship' (see also Meinert et al. 2009) to describe people's interactions with their service providers – asserting that being a client means belonging to an organization which involves expectations and obligations on both sides (2014, 56 ff.). Focusing on the exchange that these relationships actually involve is what distinguishes this concept from notions of therapeutic or biomedical 'citizenship', that instead describe people's vision of human rights or global justice and their abstract relations to an international rights framework and global polity.

What was conceptually important about disabled people's relations towards the aid agencies in Kyangwali was that their position did not fit conventional approaches to either 'clientship' or 'citizenship'. Citizens have rights, which, depending on the context, they can more or less successfully claim for. The concept of citizenship is predominantly imagined within the domains of equality and rights and in direct contrast to hierarchical and clientelistic relationships (Ferguson 2015, 236). Clients receive professional services, but have to give something in return (Whyte et al. 2014, 57). Disabled people in Kyangwali were mainly referred to, or referred to themselves, as 'beneficiaries'. Being a beneficiary, as I argue in this book, implies above all the expectation that a person will receive something 'good'.[18] Within the disability movement that promotes the slogan "Nothing About Us, Without Us" (Yeo and Moore 2003), as well as in contemporary aid discourses, the term 'beneficiary' is despised, being perceived as counter to the promoted ideals of empowerment and inclusion. Yet it is what people used on the ground, and many disabled people's experiences can actually be understood from this viewpoint.

By entering into dialogue with concepts of citizenship and clientship, I consider in which ways disabled people's positions and experiences as beneficiaries in Kyangwali also differed from what these concepts describe. For this I draw on Julia Eckert's approach that considers citizenship as something fundamentally social that develops in interactions with others, arguing that the understanding of rights and the perception of oneself as a rights-bearing subject emerge in social relations – collectively with others, or by comparison to others (Eckert 2011, 313). Based on my research, I argue that disabled people's sense of entitlement was predominantly derived through comparisons with the benefits given to other people, in other times and places, as well as

---

[18] The term 'benefaction' is derived from the Latin word *beneficium*, composed of the terms *bene* (well, good) and *ficium* (-making), and thus can be understood as 'doing good' or 'favour' (Merriam-Webster 2018).

in real-life encounters with aid workers. 'Comparative benefits', a term I use to describe people's senses of entitlement and ways of claim-making, highlights the experience and practice on a very personal level. Thinking about what they had received before, or what benefits their neighbours were given was more readily available and meaningful for my interlocutors than thinking or talking about abstract human rights. Whereas Whyte et al. (2014) assert that, within the concept of 'clientship', people predominantly understand themselves as entitled because they expect something in return for being a 'client', in Kyangwali, the comparison of benefits with other people and across other times and places took on great weight in terms of why and how people claimed assistance.

Furthermore, the relationships that evolved around Aid Global's project and people's identification with it did not emerge first and foremost from shared experiences through bodily difference, as anthropologists have observed in other contexts, termed as biomedical or therapeutic citizenship (Nguyen 2010; Rose and Novas 2008). My interlocutors in Kyangwali rather gathered as a group of people with disabilities when meetings were initiated from the top down. Meetings were not primarily used by disabled people to share their experiences, and did not noticeably shape new identities and socialities around them based on their bodily difference. When disabled people told me Aid Global was the organization that recognized them, I first thought they meant that the organization was promoting their rights, or that they talked in support groups about what it meant to be disabled. Instead, taking part in such events predominantly provided opportunities to forge connections with important people and access to material benefits. That's what my interlocutors were much more interested in than in rights-based activities such as awareness-building and training workshops.

However, when the support they expected from their recognition by the aid organizations did not materialize, the disappointment was great. At times, this disappointment took on an existential dimension, since interventions for refugees as beneficiaries, unlike aid in other settings, were based on their entire life worlds, considering that they had to build a new existence from scratch in a refugee camp. In addition, beneficiaries in general are in a much weaker position to complain than clients who, on the one hand, receive a professional service and, on the other hand, have a choice between different providers if they are not satisfied with one's services (Whyte et al. 2014, 57). This was not the case for people with disabilities in Kyangwali, where aid was much more located in the realm of charity. Not only did they lack any choice of service providers, they were also expected to be grateful for, and appreciative of, any help they received, rather than complaining about its inadequacy.

8 Opportunities and Unintended Consequences

With all these analytical tools at hand, this book also deconstructs the popular image that people with disabilities are excluded from, and receive less care and attention in, societies outside the global North. The UNHCR, for example, refers on one of its websites to refugees with disabilities as "invisible and forgotten in their uprooted communities" (UNHCR 2016b; see also Crock et al. 2017). This image is used not only for fundraising purposes, but means that aid agencies and policy researchers see such stigmas and attitudes as major barriers against interventions that aim to improve the lives of disabled people.[19] Aid Global's promotional video about their project in Kyangwali features a UNHCR representative saying: "When we speak about refugees coming from countries like Congo, it's first the cultural background [which is a problem]. In many countries in Africa we think that it is a shame to be disabled. Not just for the person, but also for the family".[20]

Yet, many of the people who had garnered one of the fancy bronze walking sticks from Aid Global liked to use them in public, and it seemed that nobody was ashamed to wear the green T-shirts and hats emblazoned with the organization's logo. Just as Adriana Petryna argues in her study about biological citizenship after Chernobyl, a deviant body in Kyangwali was not something to be concealed, but rather to be exposed and used as a resource in order to be recognized and supported (2010, 208; see also Hollander and Gill 2014). This book supports this argument, revealing how disability actually gained important significance in a refugee settlement, instead of being rendered invisible and forgotten or of creating a situation that was "nothing short of toxic". Despite the exclusionary characteristics of aid distribution that I will reveal in this book, I argue that special aid repositioned disabled people in these new communities in important ways. Even with all the challenges, life in the camp also opened up opportunities for people with disabilities – opportunities that they would not have had otherwise. Through their refugee and disability status, they could make important claims and receive assistance that was not available to either non-disabled refugees or Ugandan citizens. This demonstrates how the assumed 'double vulnerability' of people with disabilities also became

---

[19] The belief that people with disabilities had traditionally been, and continued being, locked away in backyards as a general practice and attitude towards disabled people in African and other countries of the South was robustly denounced by Benedict Ingstad as 'the myth of the hidden disabled', the title of her book on community-based rehabilitation in Botswana (Ingstad 1997; for a critique see Livingston 2005, 186).

[20] Aid Global, promotional video, shared with me in Kyangwali in July 2015.

a ‘double opportunity’: for example, in terms of my interlocutors’ search for a home outside the refugee camp, as well as in their pursuit of a more liveable future in the camp.

Ethnographies of disability in the global South have shown that the introduction of disability programmes has often conflicted with local contexts, where they did not seem to fit easily. They have shown that many African languages did not even include a word to describe individuals with different kinds of bodily impairments as a group for a long time (Livingston 2005, 10; Ingstad and Whyte 1995, 6–7). The term ‘disability’ is not easily translatable, as it conveys Eurocentric assumptions about normality and abnormality, especially in regard to what is experienced as disabling for personhood (Ingstad and Whyte 1995), and as it portrays meanings that are connected to a Western history of social exclusion, stigma and rehabilitation, but also of a struggle for political recognition.

Yet, despite its limitations, the international circulation of disability programmes based on a human-rights approach has opened up new spaces of identity building, recognition and claim-making based on the body (e.g. Berghs 2012; Biehl 2007; Nguyen 2010; Petryna 2013; Phillips 2011). In fact, the inhabitants of Kyangwali witnessed an influx of Western institutions, ideas and capital, which brought about similar trajectories to the developing welfare state: social assistance for disabled and other ‘vulnerable’ people, implementation of rehabilitation programmes, as well as a focus on sensitization about modern values, such as gender equality and hygiene promotion. Like much of the anthropological body of work in humanitarian settings, this book highlights the often undesirable outcomes of well-intended humanitarian work – although with a different focus. While much research has fundamentally criticized the medicalized perspective taken in humanitarian approaches, such as by emphasizing its depoliticizing and dehistoricizing effects (e.g. Fassin 2012; McKay 2018; Rieff 2003), I question the relevance of the apparently so promising rights-based approach for disabled people themselves.

For this, I specifically observed the shift from a more charitable towards a sustainable development approach based in rights and investigated what this meant in reality for people with disabilities in the Kyangwali refugee camp. Of specific interest for this point was the one-year Aid Global project on ‘Inclusive WASH’ (water, sanitation and hygiene) from 2014–2015. This project engaged people with disabilities to participate not only in designing various assistive technologies (e.g. accessible boreholes or special toilet seats), but also on other issues, such as challenging stigmatization, through a drama group. Futhermore, the project formed a disability association with disabled people as representatives, who assisted the project to mobilize people with disabilities for their activities and advocacy work, as well as gathering and managing data on disability in the refugee settlement.

The shift from a charitable towards a rights-based approach was rather a new development within the humanitarian world. And interestingly, anthropologists had earlier observed and criticized the trend in the other direction. Didier Fassin and Miriam Ticktin, for example, both commenting on a turn from rights to humanitarianism within French immigration and asylum politics – noting, for example, that human rights violations were increasingly being presented in terms of the suffering body. Importantly, they criticized how the medicalization of refugees and the focus on saving lives undermines claims to further social justice (Fassin 2001; 2012; Ticktin 2006; 2011a). Unlike the asylum situation in France and Western Europe more broadly, during my fieldwork I observed instead a turn towards a rights-based discourse about people with disabilities within humanitarianism, following on from the UNCRPD. In this book I will reveal the limitations and dangers of this rights-based approach in the specific setting of a Ugandan refugee settlement, especially by considering what people aim for in life and how they best can achieve it.

9 Becoming a Person through 'Building'

To address the question of what my interlocutors aimed for in life and how they could best achieve it, it was necessary to consider what it means to be a person in any particular society. Even though there is no single notion of 'personhood' in African contexts, as Comaroff and Comaroff (2001) point out, literature from different central African contexts often reveal similarities. Referring to the Tswana of southern Africa, Comaroff and Comaroff demonstrate how personhood is something predominantly social, asserting that it is acquired through building and extending oneself through relations, and that it continuously needs to be confirmed through investing in these social connections with loyalty, care and financial resources (2001, 267–269). Regarding personhood in Uganda, Scherz shows that "one increases one's standing and sense of being a full person by attaching oneself to others and by acquiring clients, not by becoming 'independent'" (2014, 2).

While values of independence and equality are central to a Western understanding of personhood, in contrast, it is hierarchical and dependent relations of patronage that are crucial in many African contexts (Devlieger 2023, 7; see also Grischow 2015). However, such artificial differentiations serve analytical purposes, while societies move along a continuum, and individuals find themselves in tensions between sociality and autonomy, which they often use strategically, as Julie Livingston argues, by striving to foster the nurturing side of the kind of dependencies they live in (2005, 5). She explains that:

> *Boaga*, or building, is an important concept in Tswana personhood and life strategy, as it is for many people in the wider African region. 'Building' continually reaffirms personhood by forging connections over time and across generations – linking the doing of today and yesterday with tomorrow. Building may mean building families, herds, houses, churches, or small businesses such as tuck shops or poultry runs; accumulating furnishings and crockery; or developing gardens or orchards. All are important markers of adulthood, responsibility and success, and all build persons. (15)

Among the Banyabwisha from Eastern Congo, of which origin many of my interlocutors were, there is a proverb: "The old man is accompanied by his good deeds". This virtue of investing in good things resonates with what Livingston explains, the other way round, as "those who earn but do not build are seen as irresponsible, unanchored, and unknowable in some ways" (2005, 15). In Kyangwali, children were considered to have an especially high personal and social value, often expressed in the way that someone was addressed as a certain child's parent, for example, as 'Mama Patti' or 'Mama Bahati'. Children needed care, but they were also a source of support and, for many of my interlocutors, their biggest concern and worry was being able to provide a good education for their children.

In this book I will show that being able to 'build' seems to be a more important marker of personhood than physical difference. This raises the question of how far the aid system and its logics and practices of distribution enabled people to 'build'. As a counter-narrative to the idea that aid keeps people in dependence and runs counter to ideas of sustainability and empowerment, I will show that, in Kyangwali, it was precisely the aid and, consequently people's positioning as beneficiaries, that enabled them to use distributions to build life projects and to invest in the interdependent relations with family and neighbours that were so crucial for them. Rather than self-reliance in the sense of independence from others, including the aid agencies, disabled people's aim seemed to be crafting a fruitful form of relatedness. Yet, on the ground the aid agencies were vehemently trying to prevent aid dependency, resulting in far-reaching, possibly unintended consequences around accepting disabled people's dependence within their social networks. While disabled people's complaints from their position as beneficiaries could well be understood as justified claims for more equality, the aid agencies usually dismissed them as unrealistic demands located in the ‘dependency syndrome’. With this, the book is an important contribution to the anthropology of humanitarian and development aid more broadly, as it compares different perspectives in a relief situation. It is furthermore a contribution to anthropological inquiries more generally, as it explores issues of personhood as they relate to the exchange of material goods and care.

10 Conducting Fieldwork with Refugees with Disabilities

During my 12 months of ethnographic research in the Kyangwali refugee camp, I interacted with 30 men and women who had paralyzed legs or walking difficulties due to polio in childhood, who had lost one or more limbs as a result of bullet wounds or burns, or had difficulty using an arm or leg or experienced pain because of an accident or chronic disease. People in Kyangwali who were not conversant in English used the Swahili words *walemavu* and *vilema* to refer to those people. Although both words derive from the description of people with paralyzed limbs, my interlocutors also used both words as an overall term for people with disabilities. They also employed the term *kajoriti* (a Swahili rendering of the word ‘casualty’) for people who had acquired a disability through an injury or accident of any sort.

Although the term ‘disability’ cannot easily be equated with local understandings of bodily difference, I have decided to use ‘disability’ as an umbrella term to mean all of the diverse bodily impairments I encountered among my interlocutors. The way the word was introduced through the humanitarian interventions in Kyangwali, and how disabled people and aid workers used it alike, also made it an emic term which carried connotations of discrimination or political recognition. Given the assumption of able-bodiedness in Uganda’s refugee approach, I did not include people with cognitive disabilities, blind or deaf people in my research. All of my interlocutors belonged to the category of ‘people with specific needs’ (PSN), but they were variously categorized in other regards, such as entitlement to special food aid. The kind of disability as well as its visibility often influenced their assumed degree of vulnerability and thus the assistance they were given.

During my fieldwork, which took place between April 2015 and May 2016, I stayed at St. Patrick’s Centre for Integral Development (SPACID), a Catholic diocese with a church and a guesthouse in the middle of the settlement, that was run by Ugandan staff. At times, other researchers were present, but mostly I met visitors from aid projects who stayed at the guesthouse for one or two nights. Often though, I was the only guest. I bought a solar panel for my own hut, as the centre's electricity was limited to just three hours in the evening, when everyone gathered in the huge living room to watch TV and drink tea after dinner.

The material used in this book was mainly generated through the methods of participant observation and different kinds of interviews with people with disabilities who had mostly fled from the Democratic Republic of Congo. The Congolese refugee population in Kyangwali was comprised of various ethnic groups from Eastern Congo, with the majority belonging to the Banyabwisha, who had fled from the North Kivu region around Rutshuru and Goma between 1996 and 2008 during the first and second Congo Wars of 1996–1997 and 1998–2003. The people who arrived after the more recent events of violence in Eastern Congo in 2012 and 2013 belonged predominantly to the Batalinga from in and around the Beni region.

I conducted most of my interviews with them in Swahili and Kinyabwisha with the help of my research assistant and translator Amani Bakunda. Amani was in his twenties and had lived for most of his life in Kyangwali, having arrived when he was just a few months old. Thanks to a scholarship, he completed his education at a Ugandan secondary school and occasionally had temporary assignments with the aid organizations in Kyangwali such as inventorying storehouses, setting up tents for an event, or identifying children with special educational needs. He thus had an immense knowledge of all sorts of aspects of the refugee camp.

I additionally carried out interviews with family members, carers or neighbours of people with disabilities, as well as with aid workers from the UNHCR, the Africa Help Mission (AHM) and the WFP. They were mainly from Uganda, but also from other diverse countries, and I was able to conduct these interviews in English. The work of the UNHCR's main implementation partner AHM was of special importance to my research, as it was responsible for the 'community services' sector, targeted at the 'vulnerable' refugee population. AHM was also the main reference point for people with disabilities, as it led the camp's health sector. I found it particularly useful to talk to half a dozen community social workers that AHM had engaged for tasks within these two sectors. Community social workers were refugees who held a position which functioned as a link between the aid organization and the refugee population. Their role was to identify 'vulnerable' people in their village, assess their needs, and inform them about any relevant meeting or aid distribution opportunity. It was often through these intermediaries that disabled people found access to the aid organizations.

During the initial phase of my research I conducted semi-structured interviews with my disabled interlocutors. The follow-up interviews I did were less structured, and eventually I collected most of my data through informal conversations and participant observation, both in daily life and at organized events. This was of great importance, as the particular institutional setting in which the interviews took place immensely shaped my fieldwork experience. When I asked my interlocutors about their life in Kyangwali, they often started to tell me how and why they had come to Uganda. As it was not the first time these people had told their story, they related what they assumed was expected from them. In doing so, they were possibly aiming to conform to a "categorical prescription of assumed needs" (Zetter 1991, 44) and navigating a context of suspicion, where the "burden of proof"[21] was prevalent. I was also well aware that disabled people saw me as a potentially promising connection who might facilitate access to resources and opportunities such as money, medicine or contacts to health workers. The perception of *wazungu* (Swahili for 'white people') in Kyangwali was associated with decision-making power and wealth: white people often occupied the highest positions within the UNHCR or visited the settlement within donor delegations. Complete strangers often approached me in the hope that I could help them with issues such as a child's education or the process of resettling to the US or a European country.

Even though ethnographic research is very different from the research carried out by humanitarian organizations, the different ways of inquiry presented a very fine line for my interlocutors. I was often equipped with paper and pencil, and when I asked about someone's experience with an aid organization, I received reactions such as: "We have already been asked the same thing you are asking me now." To avoid this, I took steps not to be associated with the aid agencies. Hence, I travelled around on a bicycle or by foot, I visited people outside office hours, or took part in activities like preparing cassava leaves for dinner. The conversations that unfolded spontaneously during such visits, but also in the market or on the way to church, were about immediate happenings and concerns, and often provided a different picture of personal circumstances to what people told me in interviews. During these occasions I was introduced to relatives I had initially not known about, or was able to observe who undertook which tasks in the household, or who came by for a visit.

Although I tried to escape my ascribed role as a humanitarian helper, my interlocutors, not surprisingly, continued asking for help. And I started reporting to the aid offices when, for example, someone had not received their food rations, when a tricycle needed to be mended, or when an individual required

---

[21] Marine Thomsen used this term in her work with Congolese refugees in Tanzania at a presentation at the American Anthropological Association (AAA) Annual Meeting in Denver in 2015.

medical attention. My interlocutors thus carefully checked that I recorded their names correctly and gave me other details from their identification papers.[22] While this brought my role closer to the aid organizations again, I also gained other additional insights into the experiences of both people with disabilities and aid workers. I observed the restricted time aid workers had to attend to refugees, the hierarchic decision-making procedures and the constant changing of schedules for planned activities. This helped me to better understand not only disabled people's frustrations and disappointments towards the lengthy and sometimes malfunctioning bureaucratic processes, but also how aid workers dealt with the prescribed working procedures.

When disabled people asked for things such as a small contribution for transport or to buy medicine, I was often unsure how to react. I feared both enforcing the already asymmetrical relations and undermining the validity of my research findings. One of my interlocutors challenged me one day, asserting that it was problematic for me to ask questions about the adequacy of the food rations without offering something to eat after receiving a negative answer. Such incidences sometimes left me wondering if the assistance was indeed insufficient, and whether I had succeeded in collecting what I initially thought of as the 'real' information.

While I sometimes helped someone out with a little money, at other times I found myself justifying that it was not my role to take over the humanitarian agencies' responsibilities or that it would create problems if I gave something to one person but not to another. Amani seemed uneasy when he had to translate my statement that I was unwilling to provide any individual help. There were instances when I overheard him saying that I had money problems at the moment, or similarly, that I was ill when I had not paid a visit to someone's place for a long time and they wanted to know why. At that point in time, I was indignant about the liberties Amani took with his translations, and came to appreciate some of its nuances only later. I was sometimes also irritated when my interlocutors demanded me to help them acquire expensive made-to-measure mobility appliances or medical referrals for surgery at one of the best hospitals in the country – especially when I compared the assistance they were already receiving to services that people with disabilities can expect in other rural areas in Sub-Saharan Africa (see also Cole 2018). I similarly felt puzzled when I visited a family with a newborn baby, taking the usual gifts of soap,

---

[22] Even though I told them I would not use their real names in my research, they sometimes asked me to do so. I have nevertheless decided to use pseudonyms throughout, as I cannot guarantee that everyone's perspective fits the characteristics of my research and its possible implications.

sugar and maize meal, and the baby's mother asked me for additional things like a hat or milk powder for the baby.

My persistent incomprehension of such situations can be understood as what Michael Agar has called 'rich points' – the moments in research the ethnographer repeatedly does not understand – suggesting a mismatch between one's own, usually implicit, assumptions about how the world works and what actually happens (Agar 1996, 31). It was only when I was preliminarily analyzing and coding my data, after a few months of fieldwork, that I realized how frequently such claims and complaints occurred and what significance they might have. What did they contain, who were they being made to, in what ways, and in which situations? What expectations did different actors have, and how did they express them? I realized that a big part of my existing data already answered some of these questions, and I tried to specifically focus more on them in the course of my research. As I reflected on these often uncomfortable experiences, I tried to understand why I felt more at ease giving someone something without being asked, as when I sometimes took bread or sugar along on my visits. And I asked myself why I felt particularly offended when I was asked for something I deemed inappropriate. I also realized that I was less reluctant to comply with someone's request for money if I felt it was reciprocated, for example when a recipient mended my broken sandal in return.

Through my reflections I became increasingly aware of my ethnocentric reasoning. In many respects, my discomfort resulted from my unquestioned assumptions about what it is appropriate to ask for, or my own expectations of how gratitude or even equality should be expressed (see also Durham 1995). I especially became more conscious of my negative stance towards charitable actions, although it was actually me who was profiting immensely from the information my interlocutors constantly gave me. More and more I began to conceptualize people's approaches towards me as crucial claims of belonging towards people who were considered potential patrons or providers, and not just as a result of my skin colour or position as a researcher that I had to overcome. I remember when the penny dropped. I had overheard one of my interlocutors asking a disabled friend for a little money to fix his tricycle. Although he had mentioned before that he was having trouble with it, he did not ask me directly for a contribution. While some weeks earlier I would have understood this situation of not being asked for help as having built rapport, I realized at that moment that it instead reflected my interlocutor's interpretation of my role as a researcher to whom asking for a financial contribution would not be appropriate in that context.

Retrospectively, I also saw the reasons behind Amani's translations as a sign of expressing respect towards our interlocutors, by retaining the possibility that I might help them, and I learnt that it was more appropriate to reject certain requests than others (see also Durham 1995). Moreover, I understood that not only actual support, but a potentially profitable connection with me could also be important for my interlocutors, such as when, for example, a woman told me that she had 'grown fat', an expression of feeling proud, when I sat with her during the food distribution session. Such a display of connectedness could, however, also play out conversely, as when one interlocutor told me that his family and neighbours might wonder why I had been going to his place for nearly a year but he had still not received a tricycle.

These insights certainly did not resolve my concerns about reciprocity and research integrity. However, rather than resisting existing social hierarchies as I had initially done, they allowed me to understand the claims from a different perspective, as a kind of sociality. On the one hand, instead of being a methodological obstacle to overcome, the way people approached me was what Whyte and Siu have characterized as "watchfulness for positive possibility" – people constantly being on the lookout for opportunities (2015, 28). On the other hand, I realized that people's requests made me feel so uncomfortable because of my culturally ingrained reluctance to enable dependency. Over time I understood that, rather than disempowerment or passivity, they signified recognition and entitlement (Ferguson 2013). I became increasingly involved in such interdependent relations with my interlocutors, which allowed them to make claims from me.

11 Structure of the Book

After this introductory chapter, the book builds its arguments over three parts, which all provide a different way of looking at how people's sociality is entangled with aid delivered through humanitarian assistance categories or disability programmes. Each part contains two substantive chapters, each of which I introduce with two case studies that illustrate the theme to be explored in the chapter. Each chapter emphasizes one or more aspects of the different logics and practices of distribution at play in Kyangwali.

In Part 1, I explore how aid for food and shelter is distributed and accessed in terms of categories of entitlement. Chapter 2, Food aid beyond survival, first discusses the vagueness of the EVI category along historical trajectories within the different institutions involved in food aid. It then explores disabled people's claims that "the food is not enough" by looking closely at everyday concerns and practices around food. I reveal that special food aid, which is calculated as a means of survival, does not treat people who cannot undertake agriculture as equals. Nevertheless, food aid is crucial for people as a contribution to their social networks as well as their survival. Based on this observation, I will show how the criteria for special food aid do not recognize and support disabled people in their roles as providers for their families. In Chapter 3, More than having a roof over one's head, I focus on the PSN category, particularly with regard to eligibility for special shelter construction. The chapter starts from the observation that being categorized in the same way does not necessarily mean equal access to aid. I will show that access and the categorization criteria often change in line with available funding and donor priorities. The chapter deals not only with shelter in the sense of having a roof over one's head, but in how disabled people seek refuge and long-term protection in a broader sense, through relations of patronage. It thus considers people's sense of entitlement and claim-making through comparisons, the aid agencies' working procedures around paperwork and categorization, as well as mistrust and what it means to be a 'good' beneficiary. I will demonstrate how access is shaped through certain moralities of exchange at different levels of service provision.

In Part 2 I broaden the focus to the daily concerns of care and work. As well as delivering emergency assistance, the service providers in Kyangwali aimed to support refugees to re-establish a home and a social existence. Yet, their actual support in this regard was limited, and service providers not only called upon disabled people's individual responsibility to become self-reliant, but additionally upon that of the families and communities in which they lived. I show, however, how the aid organizations' assumptions about individual responsibility and community support often failed to fit the reality of people's practices. In Chapter 4, Care for "people who cannot help themselves", I examine the broader category of 'vulnerable' people and consider how care was assumed and practiced towards people with disabilities in the absence of extended families. I first challenge the ideal of community support in this context and then look more closely at the ideal of an independent self that was also being promoted in terms of how disabled people were perceived as managing their daily lives. The chapter then shows how aid enabled and played into relations of care that emerged in the absence of extended families. Chapter 5, Work in view of "the life of the hoe", takes into account the concept of economic self-reliance. It reviews how the aid agencies offered solutions to people with disabilities who were largely excluded from becoming self-reliant through agriculture. The chapter highlights crucial tensions around the aid organizations' emphasis on economic empowerment through sensitization and training on the one hand, and their reluctance to provide hand-outs in line with a sustainable development discourse on the other hand. I also consider the tension that arose when disabled people became economically successful and therefore risked missing out on crucial assistance in the form of money or materials, which they could otherwise have sustainably invested in their life projects. I show how efforts to facilitate alternative livelihoods for disabled people who could not farm missed the mark by trying to 'teach a man to fish', when what was really needed were not skills, but capital, equipment, and markets.

In Part 3 I turn to the more general questions of what 'disability' and 'refugee' as categories and concepts meant for aid organizations and refugees themselves. Chapter 6, Disability as a category of difference, analyzes how the aid agencies in Kyangwali approached disability – through both a medical and a social model. I examine the varying definitions of disability and show how categories of vulnerability were not clear-cut even to those implementing them, especially since they varied according to the aims and resources available to different organizations. The chapter investigates in what ways disability served as a category of difference, and shows that, even though my interlocutors made claims on the basis of their disabled bodies, such bodies did not necessarily imply impaired personhood. I then consider what the turn to a social model of disability in conjunction with a rights-based approach meant for disabled people in Kyangwali, and point out the limitations and consequences of this shift. In Chapter 7, When the heart does not settle – life in transit, I observe disabled people's temporality in the camp and consider what the refugee category meant in relation to being disabled in people's search for a home. Taking a stance against a sedentary view, I show that people did not want to return to the place they had fled from. Nevertheless, when they spoke about "a life of suffering", they were referring to their life in the refugee camp. They drew on comparisons with a bygone home as a ground for claim-making in the present. The chapter also reflects on people's future prospects from the resettlement programme to a third country in the US or Europe, and notes the 'double opportunity' that disabled refugees had in this regard.

The topics of food, shelter, care, work and the significance of being disabled and being a refugee were not only key in the interventions being provided, but also bring the reader close to the concerns of disabled people in the refugee settlement. The case stories at the beginning of each chapter give insights into a variety of lives, dreams and histories, but at the same time build the basis for each chapter's argumentation and analysis. I also draw on these case stories in other chapters, while information about additional interlocutors provides evidence for my arguments and gives breadth and variety to my topics. As I will refer to my key interlocutors by their pseudonyms at several points throughout the book, each case story is described by three key words at the beginning, which is intended to help the reader remember better the various characters whose stories I recount. People's case stories are followed by an introduction to the chapter. Each chapter then begins by articulating a specific problem around the categorizations, before taking a closer look at people's life worlds in the refugee settlement. This balance between looking at how disabled people were approached through the humanitarian assistance categories and disability programmes, and paying attention to disabled people's wider life worlds, allows for a thorough consideration of the different logics and practices of distribution at play in Kyangwali.

In Chapter 8, the conclusion, Considering a different logic of distribution, I summarize my findings and arguments and make an overall appeal for considering a different logic, and thus practice, of distribution for disabled people in a refugee settlement. The chapter advocates taking a more differentiated view of dependency – with both theoretical and practical implications – and suggests recommendations for further research.

PART 1

∴

CHAPTER 2

Food Aid Beyond Survival

1 Case 1: Mansanga

Asylum, quarrels and grandchildren

Seated in front of a grass-thatched wattle and mud hut, Mansanga removed the skin off fresh beans that she had been soaking in a pot of water for a while. Silver-grey wisps permeated her short hair and a dirty cloth was wrapped around her waist, partly covering a loose stained T-shirt and her bare legs. Her granddaughter, about eight years old, spooned the remains of a yellow maize paste out of a big iron pot, using her free hand to cover her face every time I turned my head towards her during our talk with Mansanga.

Like most times I visited Mansanga, normally together with Amani, she was preparing food. Her grandchildren usually helped her to cook and fulfil her other household chores. For example, they handed Mansanga the maize cobs laid out on a mat to dry, so she could remove the kernels, they brought a jerry can of water that she needed to wash dirty dishes with, or they removed a heavy pot from the fire outside the hut where she cooked. Mansanga found it difficult to carry out such activities, as she had developed a stiffness in her legs as a child. She was thus used to moving slowly on her hands and knees, which was especially challenging in the rainy season when the area around the house was muddy. Her daughter-in-law Rose complained one day that Mansanga's clothes were constantly covered in dirt.

During our visit, Mansanga asked her grandson to bring her identification papers from inside the hut to answer my question about how long she had been in Kyangwali. Checking a white sheet that showed her own and her grandchildren's photos, names and ages, she figured out: "I have received [food] three times, that means I have been here for three months", according to the three dates and signatures that were scribbled on the paper. Mansanga had only recently arrived in Kyangwali, but her son Benjamin had lived in the camp for longer, together with his wife and children. It was only when war broke out again in their home in Eastern Congo that Mansanga and her grandchildren had joined the remaining family in Kyangwali. During that recent upheaval, her daughter had been killed, leaving Mansanga to take care of her grandchildren by herself.

On another visit to Mansanga's home several months later, we only found her son Benjamin and his wife Rose. Rose was splitting cassava roots with a knife and laying them out on a tarpaulin with the blue UNHCR logo on to dry in the sun. She explained that they grew maize in the field, but sold most of it in order to buy cassava, as they preferred the staple meal called *posho*[1] made out of cassava over the one prepared from maize flour. Although Mansanga had obtained refugee status in the meantime, she had not yet received her own plot of land. Instead of waiting for the camp authorities, Rose told me, they had started planting crops in the vacant land across the street from their house.

Other things had not gone smoothly in Mansanga's process from asylum seeker to refugee either. Asylum seekers normally received food rations with a 'temporary asylum seeker attestation' that was valid for three months, during which time they should acquire refugee status. Throughout my research, refugees from certain regions in Congo were granted refugee status on a prima facie basis, meaning that no individual assessment in the form of an interview was needed to obtain refugee status. But this only counted for people arriving at one of the transit centres at the Ugandan border. However, the Bubukwanga transit centre in the border town Bundibugyo where Mansanga arrived, had been closed at that time due to the low number of refugees, so she had travelled with her two grandchildren to Kyangwali by public transport. This situation created complications for Mansanga's application, and she was not able to receive food aid for nearly six months.

It was only later that I understood more about the family's problematic food supply situation during that time. Mansanga was home alone on a Sunday, as her restricted movement hindered her from attending church with her relatives. That day she told us about conflicts in the family, with a lot of bitterness: "The problem is, here at home they fight. And for me, I do not like to stay with people who fight like that. All the time you hear kakakakaka, and even when they give you food you fail to eat it. The fighting is every day, they always fight with that woman [her daughter in law]". Again, she showed us her refugee attestation card, and said that, thankfully, she had received food rations again a few months ago. Although there were other reasons for family quarrels, Mansanga expressed how much her being off the food log had intensified the already existing tensions: "This woman has said several times that I ate their food, but I did not add anything. The food in the house was already little, and I felt bad, so I would even refuse to eat. At least now, somehow we have enough food".

---

[1] *Posho* is the Luganda name (in Swahili *ugali*) my interlocutors used to describe a staple meal (porridge) made out of maize.

Early in 2017, when I dropped into Mansanga's home during a short visit to Kyangwali, I found it nearly double its former size, with an expanded house full of people. Benjamin had started a small bar where he sold *kaveras* (small plastic sachets) of diverse liquors, and played music from stereo equipment powered by a solar panel. Mansanga was again processing maize from the field, with other women in front of the hut, next to a newly-built outdoor kitchen. Someone passed by on a *boda boda* and bought maize, while a cyclist sold dried fish out of a basket to the family. "*Maisha si mbaya*," life is not bad, they said, as business was going well and they were even able to sell the surplus maize from their fields.

2 Case 2: Rafael

Begging, good neighbours and Mother Mary

I learned about Rafael from an aid worker from one of the NGOs in Kyangwali. She told me that they had helped him through a gardening project, as he was an elderly disabled person living on his own. So Amani and I rode our bicycles along the narrow paths that led away from a village primary school, as we had been told how to find him. However, even asking around did not help us much, until we realized that Rafael was known by the name *Mapiki*, as people referred to the bicycle he used to be seen with.[2] We finally found him by his small hut directly beside one of the paths, sitting in front of his open door on a plastic mat. He greeted us with his partly toothless, but bright smile, happy to have visitors, which he thanked Mother Mary for. His wrinkled face and grey hair contrasted with his bright blue hip hop-style hoodie and the glaring yellow plastic rosary around his neck. His knees were drawn up to his chest and he seemed to experience pain when he moved his posture much. His hands and feet were malformed, his knuckles thick and swollen, the toes only short stumps – due to a parasitic skin disease caused by sand fleas, as I later learnt.

Rafael had fled from Congo to Kyangwali 19 years earlier. Although he was already in his older years by then, he used to farm. He planted maize, beans, Irish and sweet potatoes but, after the misery, as he called it, he was no longer able to work. One night, about four years before, he had suddenly developed pain and stiffness in his legs and knees. Since that day he had never again been able to stretch or move his legs, and he became highly dependent on other people's help. He said he was lucky that some neighbours helped him

---

[2] *Pikipiki* is the Swahili name for a motorcycle (although Rafael used a bicycle).

out: "They cook for me, and they wait and take me to bed when I'm done eating. Sometimes, it is better for me not to eat much because that helps me not urinate or defecate at night, as I cannot move myself and no one is there to take me [to the latrine] at night". Referring to one neighbour called Mohammed, Rafael explained: "He helps me in various ways. Like, when I am thirsty, he brings water and he always carries me to bed. He even gives me money, sends his child to fetch water for me, they collect firewood from the forest, and he chops that firewood for me. This man cares for me and looks after me well".

When Rafael's bodily capacities diminished after the incident four years previously, the aid agencies had categorized him as an 'extremely vulnerable individual', an EVI. Hence, Rafael was still receiving 100 percent of food rations every month even after 19 years in Kyangwali. At first, the village community social worker collected the food rations for him. Rafael then gave these rations to Mohammed, whose family in turn cooked for him. But things had become problematic: at one point the community social worker had stopped delivering the food rations, and then suddenly vanished one day – unfortunately with Rafael's attestation papers and food ration card, which meant that he missed out on his food rations for three months. Ever since then, Mohammed had collected the food rations for Rafael. However, despite receiving the rations, Rafael complained: "I receive food for one person. Oh my God, a little oil, which they can only cook with for two days. CSB [a corn and soy blend used to make porridge] only lasts for three days. Then they give me three cups of beans for three days". Rafael shared his thoughts about why his neighbours helped him out: "They help me because they see that I cannot live without their help. When they give me food and porridge, they say that I can die for other reasons rather than hunger".

When we returned another day, we again found Rafael in front of his hut, smoking a pipe. We heard that he sat in this spot every day, sometimes begging for money from the people that passed along the small path leading through the village. Often, his neighbour's children surrounded him, and Rafael explained: "When a Good Samaritan gives me some money, I send a kid to the market to buy some fish or tomatoes for me". During a conversation with Rafael's neighbour, Mohammed was eager to emphasize it was he who took care of Rafael, and that other neighbours were "just talking", implying that they did not actually support Rafael as they claimed. Mohammed had taken on the responsibility after a man who used to look after Rafael had received the opportunity to resettle in a European country. When I asked about the ways he took care of Rafael, Mohammed answered: "He is like my child. I always plan, whether it is medication, whether it is food or clothes. I plan for him like I plan for my children".

As Mohammed viewed it, his own children had never seen their grandfather, so he told them that Rafael was theirs, saying: “They feel happy to visit their grandfather. When I go to work they check if Rafael has eaten or if he has water”. Later in that conversation Mohammed referred to the three months when Rafael did not receive any food rations: “In those three months, I struggled with Rafael and those 12 kilograms of maize would have helped me with buying soap, it could have helped me with medication so that I could get a way to ease life for him”. Although stating that the food rations would have been helpful, he complained about the amount of food disabled people received: “The way Rafael or any other person receives that 12 kilograms of maize, it cannot last for a month or even ten days because it is very little. So those who have somewhere to dig – like me, I can dig – are lucky. But that maize alone cannot be enough, not even for a child’s school fees”.

∵

When one thinks about humanitarian aid, food is one of the first things that come to mind. Food is what people need to survive. As such an essential part of disabled people’s daily lives, it was frequently one of the first things they brought up in our conversations. Food aid was also omnipresent in Kyangwali as, for example, hut doors were created out of oil tin cans with the blue World Food Programme (WFP) logo on, children carried jerry cans that had once served as oil canisters, and white sacks with the red and blue USAID emblem were piled up for sale in small retail shops and in the market.

The cases of Mansanga and Rafael show how food aid becomes integrated into people’s everyday lives through practices of cooking and eating, as well as through sharing, parenting and other forms of care. In this chapter I explore the rationales of food aid for disabled people in Kyangwali, and relate it to their life worlds. I consider people’s concern that “the food is not enough”, as they often complained, and reveal how my interlocutors challenged the logics that guided food distribution. The chapter demonstrates that food is not only essential for people’s survival, as conceptualized by the aid agencies, but also becomes part of people’s sociality when they sell, exchange or contribute food rations within their social networks.

Food aid to Ugandan refugee settlements in Kyangwali was provided by the WFP, but stored in big warehouses in the different camps and distributed through a partner NGO. As Uganda’s government allocated land to refugees for cultivation as part of their self-reliance strategy, the WFP gradually scaled back their relief operation by reducing the amount, and eventually phasing out their food rations for people who were able to make use of the land and earn an income through agricultural or other livelihood activities. However, people who struggled to use the land efficiently due to their health status, age, mobility or the number of dependents they had to care for, were categorized as 'extremely vulnerable individuals' (EVIs) and entitled to special food aid. They continued receiving the 100 percent of the food rations indefinitely, no matter how long they had been registered in the refugee settlement.

The category of the 'extremely vulnerable individual' was just one of many used to allocate food rations in Kyangwali. Based on the latest assessment mission for food security in 2014, the UNHCR, the WFP and the Office of the Prime Minister (OPM) had developed their current 'food ration schedule' for Kyangwali by categorizing refugees into the following further groups. The categories 'asylum seekers' and 'new arrivals' designated people who had lived in the refugee settlement for less than three years, the category 'new case load' denoted people who had arrived within the last four to five years, and the category 'old case load' stood for people who were registered more than five years ago. People from the 'new case load' and the 'old case load' were entitled to 60 percent and 50 percent of the food rations, respectively (GoU 2014).

As the provider of food aid, the WFP calculated the rations according to the daily calories needed to sustain human life. The recommended minimum was 2,100 calories per day, and this is what a refugee on a 100 percent food ration in Uganda received (The Sphere Project 2011, 185). These required calories were provided in the form of maize, beans, CSB (a corn-soy blend to make porridge), vegetable oil and salt (GoU 2014). In the monthly food distribution of October 2015, the UNHCR and the WFP introduced the option of choosing between food aid and an equivalent of this support in cash in Kyangwali. This was part of a new approach that the aid agencies had been gradually implementing since 2014 in the various refugee settlements in Uganda and worldwide. The shift towards food assistance provided in the form of cash aimed to empower refugees by allowing them to choose what they wanted to eat themselves, and had so far been considered extremely successful (e.g. WFP 2015).

Given this basic information, in this chapter I will first outline the rationales that underlied food aid for people with disabilities and reveal their vagueness, as a result of different historical trajectories of the concept of vulnerability in various institutions. By looking closely at everyday concerns and practices around food, I will then expose how disabled people were critically excluded from participating equally within Uganda's overall refugee policy, since food aid only ensured survival, and did not enable people to become self-reliant. In a third step I will show that, despite this shortcoming of food assistance for disabled people, food aid was important for enabling people to create and maintain social relations. Thus, the higher food ration received by disabled people not only represented a contribution to their social networks but, as a regular and stable form of support, it could provide security in contexts of uncertainty.

3 Vague Rationales of Food Aid for Disabled People

The basic rationale behind food aid in Kyangwali must be understood in relation to Uganda's self-reliance strategy. In a policy context where people were expected to become self-sufficient through agriculture, those who were unable to do so were entitled to special food support, as outlined above. Behind this rationale is a Western ideal of equality that aims to level the playing field (Ingstad and Whyte 1995, 7–8). "People are thought to be in need," Stone argues, "when they do not have whatever it is that most people in the society obtain through their work" (1986, 20). This kind of logic is also ingrained in Uganda's categories for food aid. Under the current self-reliance strategy based in agriculture, the provision of food aimed to level the playing field for people who were not able to farm their fields.

However, the UNHCR and the WFP did not perceive disabled people to necessarily have special food needs. The eligibility criteria for people with disabilities stated that: "A person qualifies for food assistance, if he/she is unable to access food due to the direct consequence of his/her disability and doesn't have family and/or external support".[3] This description was attached to two different criteria that counted for any person potentially being categorized as EVI. The first one stated that, if a single head of a household was considered unable to access food, all their children aged 18 or under qualified for the so called 'food-basket', meaning they all would receive 100 percent of food rations.[4] The second additional criterion stated that someone was only entitled to special food aid when he or she did not have any household members older than 18 who were seen as able-bodied and economically productive.[5] With this, vulnerability, or rather inability, as the criteria explicitly state, was socially defined. If disabled people had support from an able-bodied spouse or a grown-up child, they were seen as being able to access food, and thus excluded from special food aid.

The people I talked to in Kyangwali often did not themselves know why – or due to which criteria – someone was categorized as EVI or not. Often they

---

[3] Document 'Selection Criteria for WFP, EVIS', received by email from a UNHCR aid worker, February 12, 2016 .

[4] Document 'Selection Criteria for WFP, EVIS'.

[5] Document 'Selection Criteria for WFP, EVIS'.

simply referred to their status as “being on the list”, which was equated to being on the list for food aid from the WFP. The vagueness about who was entitled to food aid due to which criteria also resulted from the EVI status being both an individual one, and concerning the household. The EVI category was, as the name suggests, framed around an individual’s status. Yet, the eligibility criteria were thoroughly entangled with the circumstances of an individual’s household. Mansanga received 100 percent food rations initially as an asylum seeker and later as a newly-arrived refugee for herself and her two grandchildren who were registered along with her. Although Mansanga shared a household with several other people, what counted in terms of food assistance was the number and constellation of people that were on her refugee attestation card. If she had been on the same attestation card as her adult son, she would not have been eligible for special food aid.

During the time of my research the WFP struggled to move away from the EVI category to EVH, standing for ‘extremely vulnerable households’, as they were in fact distributing food to households, not individuals. In Kyangwali and beyond, however, the documentation about selection criteria for food aid still used the name ‘EVI’, and this was also the term which aid workers in Kyangwali used all along. These respective foci on the individual or household led to much confusion in applying the categories and in interactions between the various organizations. This can be attributed to different conceptualizations of vulnerability and a vague definitional authority over the inclusion and exclusion criteria.

When I approached a WFP representative in the country’s head office in Kampala one day, with two different definitions and criteria of the EVI category – documents which I had obtained from different UNHCR officers – she reacted with surprise, as she was only aware of one of them, the one defined by the WFP (although the WFP logo also featured on the second document). The UNHCR had used the EVI category since the 1990s in most of its operations worldwide (Glasman 2015, 15), but it was particularly significant in the context of Uganda’s refugee self-reliance policy with its reduction of the initial food rations for most refugees after a given time. Its current definition was a product of this policy, and its defining criteria were determined by the WFP, as they were the organization providing food aid. A UNHCR representative explained this situation as follows:

> Well, when we look at the WFP, the list that we generate after verification is actually regarding the EVIs who are in need of food support. But there are also EVIs who are in need of medical support, educational support or

> shelter support. So there are also the general UNHCR criteria that target specific different angles and different aspects of our interventions.

Within the UNHCR's operations worldwide, the EVI category was used in a broader way than only concerning food support. When they categorized someone as 'extremely vulnerable', it meant that they gave that person priority in every possible regard.

The concept of vulnerability had arisen from different historical trajectories in various institutions. While all aid interventions in refugee camps rely on principles of vulnerability, some institutions used the concept at the population level, others at the household, or the individual level, given the aims and roles of each institution (see e.g. Heijmans 2001). Vulnerability as a category was initially used to assign priority food aid in contexts of humanitarian emergencies, and it just referred to nutritional status (Davis 1996; Jaspars and Shoham 1999). The UNHCR initially developed as an institution that offered legal protection for European refugees after the Second World War, and only began categorizing people according to their basic needs and vulnerability when the institution expanded globally in the 1990s (Glasman 2015, 15). When it incorporated the concept of vulnerability into its approach, the UNHCR borrowed from other UN organizations (such as the WFP, WHO and UNICEF), but especially relied on organizations that prioritized aid recipients' personal medical needs (such as ICRC, Save the Children, Oxfam and MSF) (Glasman 2015, 15–16). Their concept of vulnerability was thus predominantly about individual bodies and risks.

In the WFP, vulnerability was generally understood in terms of nutritional risks. Within their 'Vulnerability Analysis Mapping' (VAM) process, vulnerability was interpreted as food insecurity and rather an assessment of households or even whole populations. It not only covered food availability, access and use by vulnerable populations, but included food markets, regional commodity flows and population trends (O'Connor et al. 2017, 8). Thus, while vulnerability was in one sense narrowed down to mean simply access to food, it was in another sense broadened out in comparison to the UNHCR's historically-evolved approach, which focused more on the individual person. Therefore, I argue, the varying and vague categories in place in Kyangwali stemmed from historically differing uses and adaptations of the concept of vulnerability within the WFP and the UNHCR.

Next, I turn my attention to an alternative perspective of how food aid should be conceptualized, by considering how my interlocutors understood their own vulnerability within Kyangwali's refugee policy context.

4 "The Food is Not Enough"

It was a colourful happening. As well as the famous *kitenge* dresses and headscarves bearing flamboyant designs, many of the women at the refugee settlement's food distribution point were protecting themselves from the blazing sun with fanciful umbrellas. The glare from white sacks of beans and maize emblazoned with the WFP logo was almost blinding, as they were unloaded from the lorries and stacked up on a huge tarpaulin on the ground. People coming to collect their monthly allowance lined up, carrying all sorts of differently-coloured plastic basins, buckets, jugs and mugs to transport their food rations in. Through a loudspeaker, an aid worker announced that this month's food allowance contained the full portion of maize meal, soy, beans and cooking oil, but he also brought the not so happy news that there was no salt available this time. Indignant murmurs swept through the crowd but soon gave way to relaxed chattering and friendly greetings again.

From afar, I was able to spy Odongo. With his small paralyzed legs crossed, he sat on one of the distributed sacks in a group of people that were about to divide their respective shares of the food rations. As well as a woman with a limping leg, the group included elderly people and children. I was told that they were a group of EVIs. When I sat in the circle of Odongo's group, as they divided the food aid into their individual rations, I was not surprised to see them quickly buy and sell amongst themselves and with others. As I had observed in other situations, food distribution points became a big market place, though no one called out to advertise their merchandise. Trading food aid was prohibited, and people were constantly reminded of that by announcements over the loudspeakers, and the instruction 'NOT TO BE SOLD OR EXCHANGED', which was printed in large letters on the huge cans of vegetable oil.

Whilst dividing the mixture of corn and soy blend (CSB), Odongo and a young boy laughingly complained about how small the rations were. When they noticed my interest in the topic they went on to make jokes about having to count every single bean for a meal, claiming that, as refugees, they were not supposed to eat much. This was not an unusual situation to encounter in my fieldwork. During food distributions, strangers often turned towards me and complained by placing their hands on their bellies, articulating that "the food is not enough". Also, in personal conversations many disabled people and their families or carers stated that the food rations they received were too small. While some of my interlocutors referred to the kilograms of maize or beans they received, they often expressed the amount of food in cups and communicated it in the form of rhetorical questions: "See, four cups of beans and 12 kilograms of maize, can you eat it for a full month?" or "One cup of oil, can you, if they gave it to you, eat it for a whole month? It is not possible". People with disabilities argued that the food rations would only last for few days, maybe for one or two weeks, but definitely not for the whole month, even if they only ate twice a day.

Initially, I considered some of these statements that the food rations only lasted for few days to be wild exaggerations. I was well aware that my perceived role as a potential helper or advocate in my task as a researcher might shape people's complaints about the amount of food rations towards me (see Schuler 2018). Ugandan aid workers never missed an opportunity to remind me that white people like myself were associated with decision-making power and money. Assuming that disabled people were just lying to me to make a point, the aid workers emphasized that food rations contained sufficient calories to sustain human life.

When the ever-prevalent complaints that the food was not enough did not reduce or vanish after I spent considerably more time with disabled people and their families, I realized that they implied more than simply being a question either of the amount of the food or of my skin colour. Anthropologists have shown in other displacement contexts that the sufficient, but 'wrong' food can become an indicator of what is absent. They use expressions like "tastes of necessity" (Trapp 2016) or "foods of sorrow" (Dunn 2014) to describe food aid that does not match people's eating cultures or preferences, so is not capable of sustaining social connections, normalcy and dignity (see also Oka 2014). This certainly played a crucial role in how my interlocutors perceived and valued the food aid provided by the WFP. Yet, focusing on disability, there seemed to be more at stake. When I started to become increasingly interested in the ways in which disabled people understood the food as not being enough, I learnt not only about the entanglement of food aid with people's socialities, but also about how people challenged the current logics of distributing food aid.

One day when I visited Vitali, an elderly Burundian refugee with paralyzed legs, he complained about his health. Rather than considering the pain in his arms, neck and chest or his decreasing sight as infirmities of old age, he was convinced that it was the poor food that was impacting negatively on his body. He explained that he ate *posho* and beans on a daily basis, and did not have the money to buy fruit and vegetables to at least acquire some vitamins. While we talked, a neighbouring girl entered the hut and put a pot in front of Vitali. After she left, he opened the pot and said, "you see, *posho* and beans again," before putting it aside to eat later. The neighbouring woman who cooked for Vitali also expressed her concerns about the food they ate day in, day out:

> You cannot eat beans and *posho* every day, and they [the aid agencies] do not give us charcoal, they do not give us salt. And they do not give us

> money to go and grind the maize. I have a small business that helps me, so I can at times get things like meat, sugar or fish. You cannot eat these beans every day and it cannot take you through the month. It is impossible, it can even cause sickness in your body.

The expression that "the food is not enough" also points to the fact that what was being provided was not thought to be the right food: the maize was whole, so had to be ground before it was edible, and my interlocutors wanted more diversity in their diet. Mansanga's and Rafael's examples demonstrate the ways in which food aid was exchanged or supplemented by other goods, which people considered to be more tasty. Mansanga's daughter-in-law usually sold maize in order to buy cassava flour, which they preferred for making *posho*, and Rafael sent his neighbour's children to the market to buy fish or tomatoes if he managed to receive some money from one of the people who constantly passed his hut.

When I talked to a WFP consultant about the problem that the food provided often did not meet people's eating preferences, she eagerly agreed that food support should be adapted to fit what people really wanted. Yet, she also explained that this was simply not possible for the organization to fulfil within its funds and remit. Due to budgetary constraints, refugees were expected to adapt to the most economical provisions, the most nutritional and caloric food available for the lowest price on the world market (Trapp 2016, 414). This sometimes became explicit when the sacks of soy, for example, carried the inscription, 'Supplied by the USA'. The people I interacted with knew that they ate rice that came from Brazil, for instance, but also sometimes from Uganda or Rwanda. Governments were by far the largest group of donors to the WFP, contributing either in the form of cash or in-kind donations (WFP 2016b). When such donations were in cash, a WFP representative informed me, the organization prioritized buying food locally and tried to adapt to people's ordinary eating habits. Yet any kind of donation counted as significant, so food donations were being transported from different parts of the world to the refugee settlement, when people in Kyangwali actually often produced a surplus which they sold very cheaply in the local market (Omata and Kaplan 2013).[6]

---

[6] According to a WFP consultant, most of the donations the organization received were in-kind donations, specifically from the US in the form of maize and red sorghum. The WFP's Standard Project Report 2016 (no earlier publications were available) does not list any in-kind contributions by donors, although it does state that in-kind donations of food commodities in 2016 included fortified maize meal, vegetable oil, grains, pulses, specialized nutritious foods and high energy biscuits (WFP 2016a).

Disabled people expressed the uniformity of the food aid provided in terms like, “We eat like refugees”. They usually sold part of their food rations, or supplemented them. Almost all the disabled people I talked to had a plot of land because, as with food aid, the plots were allocated to households rather than individuals. So in most cases, close family members of my interlocutors cultivated the fields, primarily with maize, beans, cassava, sorghum and potatoes. For people from Eastern Congo who made up the majority in Kyangwali, the food aid enabled them to cook one of their staple foods, a basic maize porridge accompanied with beans that was normally eaten twice a day.[7] But whenever possible, people supplemented this food by adding predominantly tomatoes, onions or carrots to the bean sauce or by augmenting it with small dried fish. People also found variations in terms of cassava, potatoes, sorghum or plantains, and supplemented their diet with fruit like mangoes and bananas, which they sometimes grew in their fields. The importance of the right food came to the fore when “things are going well” (e.g. when an individual’s business brought in income, or when someone was lucky enough to receive money from a relative abroad), which was often reflected in what kind of food people ate. Sugar, tea and other things that usually needed to be bought, like meat, chicken or additional salt, were celebrated as delicious luxuries.

However, sometimes the aid workers accused people of “play[ing] with their nutrition” if they sold food rations, as they were specifically calculated according to a person’s caloric and nutritional needs. One of the aid workers said: “I cannot really understand, if it [the food ration] is enough or not. To me, it should be for the individual to know: if it is for a month, they should use it accordingly”. Aid workers doubted the capacity of many refugees to use their food rations responsibly. This was seen as particularly problematic when cash was introduced. Although the service providers generally approved of the fact that cash distribution enabled people to choose the food they preferred, many aid workers expressed certain concerns.

Despite their claims that food money was often spent, for example, on alcohol, I observed that people behaved very responsibly in how they used food aid or cash donations. A disabled mother of five weighed up the potential consequences for her children’s nutrition when considering whether to choose food or cash donations: “I imagined getting the money because it is more for the vulnerable. But the flour for porridge … when the children go to school they

---

[7] Compared to Congolese refugees who might count themselves lucky that maize was a surplus product in the American food market, the eating customs of South Sudanese refugees clashed rather sharply with the food aid provided. They were used to eating meat and dairy products, in line with the main livelihood of cattle keeping in their home country.

need porridge. Where will I get it from? Will they just drink plain water? They will get malnourished". This woman explained that it was sometimes difficult to find the flour she wanted for the children's porridge in any of the shops or markets in Kyangwali. Some months later, she told me that she had switched to cash, because she found that the money allowed her to buy things like paraffin, charcoal, soap and sugar, as well as some food – as the family harvested a big part of the food they needed from their own field. Similarly, the people I knew seemed to use cash donations, like the food rations, in very thoughtful ways.

Many of the people I talked to switched to cash donations over time, arguing that this not only allowed them to choose which food to buy, but also meant they could use a small amount for other requirements. People categorized as EVI received 36,000 Ugandan shillings[8] per month, people categorized as 'new case load' were given 28,000 Ugandan shillings,[9] and those included in the 'old case load' got 15,000 Ugandan shillings.[10] It is important to note, however, that not every person with a disability had the same opportunities to access shops and markets, in regard to their mobility or a social network they could draw on. The option of receiving cash turned out to be especially handy for disabled people who ventured into business, because this enabled them to invest in their business, or even start one, at times when there was enough food in the house from their fields.

The option of cash also brings up questions about who has the freedom of choice within households. Cooking was clearly a woman's domain in Kyangwali. None of the men I knew cooked for themselves. Their meals were prepared either by their wives, their children, or neighbours. As cash distribution was only introduced over halfway through my research period and, as most of my interlocutors only switched to that at a later point, I was not able to observe many consequences in this regard. Nevertheless, some accounts pointed towards a certain direction. When I asked their opinion of cash support, some of the women thought that it was a money issue, which would be the men's domain to decide. Many of the married disabled women I knew handled money as well as their husbands, or also engaged in business activities. Yet it is possible that cash implementation might have a gendered impact.

---

[8] Approximately 9 US dollars.

[9] Approximately 7 US dollars.

[10] Approximately 4 US dollars.

5 Special Food Aid: Not Enough for a Child's School Fees

Another way that people perceived the food rations as not being enough was explicitly expressed by Mohammed when he said: "But that maize cannot be enough, not even for a child's school fees". Another of my disabled interlocutors similarly explained: "All my children receive the food rations. But because the children study, we need to pay like 15,000 Ugandan shillings[11] at school. When you remove that money, you are left with little food". It was a widespread expectation that food aid should provide for people's needs beyond nutrition. However, this anticipation clashed with the reality that the food rations were definitely not enough to fill a person's stomach and provide for their other needs.

When my interlocutors argued that "the food is not enough", they were referring to the fact that, through the food aid allocation, they were not treated in an equal way to non-disabled refugees. The food support that disabled people categorized as EVIs received was not actually in any way equivalent to what an able-bodied person could acquire through farming. While a big part of Kyangwali's population still received at least a percentage of the initial food rations, their agricultural activities enabled them to sell part of their produce in order to cover other needs such as soap, *airtime* for topping up mobile phone services, clothes, school fees and medicine. Disabled parents and their spouses often feared that their children would have to drop out of school in order to cultivate land, since they were unable to do it themselves. They felt it was unfair that the aid organizations did not provide them with more food, or at least support them with their children's school fees and study materials. While farmers could acquire necessities other than food as soon as they produced some surplus through farming, the food aid people with disabilities received targeted just their nutritional survival, so did not meet such other needs. It was in this sense that the categorization system did not fulfil its rationale of creating equality among supposedly autonomous individuals.

Most disabled people's position of not being able to grow crops also conflicted greatly with the fact that they received the same food support as everyone else among the newly-arrived refugees: "The food they give us is not enough. We get an equal share with people who can go and dig. People with disabilities should get more food than those who can support themselves,"

---

[11] Approximately 4 US dollars.

argued a father with paralyzed legs. Until refugees had their first harvest, or even for longer, they were all considered as disadvantaged in terms of making a living. But, like the people who were soon able to cultivate their fields, my interlocutors still only received the 100 percent of food rations that provided 2,100 calories. Despite their disabilities, they were not entitled to any additional food allowance, which amounted to critically excluding disabled people from participating equally.

In theory, disabled people who had just come to the camp were treated slightly differently from other 'new arrivals', receiving a different composition of their 2,100 calorie allowance. While able-bodied 'new arrivals' received 400 grams of maize grains, 80 grams of beans, 30 grams of vegetable oil and 50 grams of CSB, people in the 'EVI' and 'asylum seeker' categories received 390 grams of maize meal instead of maize grains, only 70 grams of beans, but an additional 5 grams of salt. This meant that people in the latter categories did not have to invest money to mill their maize or acquire salt on their own. During my field research in 2015 and 2016, however, the EVI category among newly-arrived refugees did not exist, and everyone simply received the 100 percent food ration in its normal constitution. According to the UNHCR and the WFP, EVI assessments to verify the current list and add new refugees should ideally take place twice a year, but this had not been done in Kyangwali since July 2014 due to budgetary constraints and coordination challenges. Hence, people with disabilities who had arrived between 2014 and the end of 2016 received their maize unground. In order to make this food edible, they required money, or had to give a specific amount of their food ration as payment to the local grinding machine operators.

In my conversations with aid workers from different organizations, there was no mention of the problem that disabled people did not have the assets to afford other expenses without practicing agriculture. When I discussed my preliminary research findings with Uganda's WFP officers, it soon became clear that it simply was not possible to increase the quantity of food rations for 'vulnerable' people. They immediately explained that the WFP had to stick to the global standards, which defined food rations as a means for survival.

Thus, despite their disabilities, my interlocutors were not entitled to any additional food allowance. This meant that disabled people were not enabled by this system to participate on an equal basis. The Ugandan refugee policy's stated objective was self-reliance, but the food aid provided for those categorized as 'extremely vulnerable' merely targeted their survival. Understanding how the food was considered not enough from the perspective of disabled people in Kyangwali makes it more imperative to grasp how concerns and complaints about food, which played an essential role for all refugees in Kyangwali, were specific to people with disabilities. The examples in these last two sections show that my interlocutors' assertion that "the food is not enough" encompassed more than simply an account targeted towards the quantity of food aid. Rather, it was a statement of how disabled people understood their vulnerability within Uganda's refugee policy of self-reliance and their role within their social network in terms of providing and fulfilling responsibilities.

6 Food Aid as a Contribution

Even though people argued that the food aid was not enough, it was still a very valuable contribution to their lives in several ways. This became clear when I saw what happened when food aid was absent. During the months when the elderly woman Mansanga did not receive any food rations, tensions arouse in the relationship between herself and her daughter-in-law. Rose complained that Mansanga was a burden when she could not contribute to the household's food. The way that food rations contributed to Mansanga's acceptance within her family shows how they played a crucial social role. Like Mansanga, several of my other interlocutors were – at least temporarily – not categorized as EVI, due to their household constellation. For most of them this was because they had an able-bodied spouse or grown-up children in their household or, more importantly, on their attestation card.

The main reason why the criteria for being categorized as EVI involved family or external support as an excluding factor lay in the overall pursuit of avoiding dependency. Aid organizations in Kyangwali feared the withdrawal of community or family support when they gave disabled people food rations. One WFP representative argued: "I have seen that the assistance given to vulnerable people draws other members in the community away from them, from supporting them. If they are provided with that kind of assistance, it is already an indication to the community that they have enough support". The aid agencies' assumption was that families or others should support disabled people in acquiring food. This led to the contradiction that, while the service providers were trying to reduce dependency on aid, they accepted people's dependency within their families. Claire, a woman who had lost both a leg and an arm during shootings in Eastern Congo, explained how she was not listed as an EVI for several years:

> They had refused to put me down as 'vulnerable', because I have a husband who should work and take care of me. They said that it was impossible to give me food. I came to see my name there after how many years?

> Seven years! I was really so disturbed. I wondered if my husband would abandon me, because he was the one trying to support us all that time.

By having family support as an exclusion criterion that prevented people from receiving special food aid, the EVI category only recognized certain vulnerabilities, while neglecting or possibly even creating others. Claire felt that being forced to depend on her husband had left her even more vulnerable.

By having to rely on family and community support, disabled people were not only deemed to be dependents. Moreover, their role as providers was neglected. A disabled father worried that: “There comes a time when they remove you [from the food log] and say your children will support you, the adult children. But the problem with the older children is that they are at school and instead it is you who should be helping them”. The criteria for the EVI category overlooked the point that disabled people only perceived themselves as being treated equally when they were enabled to carry out their roles of looking after their children, like anybody else. Also in this sense, for many, “the food was not enough”, as they received the reduced food rations of 60 or 50 percent because they shared a household with an able-bodied spouse or adult children.

I mentioned before that many of my interlocutors had dropped off the special food allowance list temporarily. During my fieldwork period, most of them were actually (again) categorized as EVI, even if they were living with an able-bodied spouse or grown-up children. This obviously contradicted the EVI conditions, but aid workers thought it was important to apply the categories in practice by carefully scrutinizing each respective case, instead of sticking strictly to the criteria. One of the aid workers said:

> These are standard guidelines, but there are situations that may differ. If we look at family support, there might be family members around. However, we have to consider what the situation of the family members is. An old man or woman is for example abandoned by their children, or the daughters have married and are influenced by their husbands, so the support for their father or mother is limited.

At one point I learnt that the aid agencies in Kyangwali had received complaints from the WFP that their number of EVIs was increasing too much. This might – at least partly – have been an outcome of well-meaning aid workers using their autonomy to alleviate the far-reaching shortcomings of the EVI category.

Food aid as an important contribution to an individual's well-being should not only be grasped in quantitative terms. Especially in a context of insecurity, it can also provide reliability. One of my interlocutors emphasized: "Food from the garden takes long to grow, but food from the distribution only takes one month, and then you have something to feed you, it's as simple as that". Without food aid, people's food security was dependent on the harvest time itself, but also on how good the season was for cultivating specific crops. Sifa, who had a limping leg, received food rations as an EVI even after living in the refugee settlement for over ten years. She also described the food rations as being especially important when there was a poor season and she and her sister could not grow enough food in the field. She explained: "My brother, he can help, but it is not much. We cannot go to him every time we have food problems".

Personal relationships always involved some kind of uncertainty, as people could never be sure how significant others were willing or able to react in certain situations. Rafael, for example, could only hope that his neighbours would support him when he had nothing to eat. Whyte and Siu speak about "personal contingencies" to describe this kind of dependency, which bears both potentials and uncertainties (2015, 19). My interlocutors informed me about problematic situations, such as when a certain family member fell sick and was not able to work in the field for a while. The downside of such relationships also became clear when, for example, Rafael did not receive food rations for a while because the village's community social worker had not done his work honestly.

Given these dependencies, food aid took on a specific importance in people's lives as being something stable and regular, in contrast to the unpredictable help from significant others and agricultural uncertainties. Whyte and Siu suggest that dependence on institutions seems to be more reliable than interpersonal dependencies (2015, 22).[12] Accessing food aid was thus able to provide some stability, and not just for the person who received the food rations. Because it was a comparatively regular and stable form of support, entitlement

---

[12] It needs to be mentioned that humanitarian food aid could also entail some kind of uncertainty. Due to inconsistencies in food provision logistics, the proposed food ration schedule could not always be relied on. It sometimes happened that cooking oil or salt were not delivered, or that, as described before, the maize came in an unground form. People were also often unsure of exactly when the food would be delivered, or if they were facing delays of several days, when, for example, the lorries could not drive along the muddy roads to Kyangwali in the rainy season. Furthermore, cuts in WFP funding due to global or national displacement dynamics repeatedly affected food deliveries to Kyangwali, resulting in food rations being unexpectedly and temporarily reduced to half the usual amount.

to the full amount of food rations could also be essential for receiving further help, as Rafael's case shows. Rafael argued that it would be difficult for Mohammed's family to take care of him, if he did not receive rations. A community social worker made the same observation when he asserted: "If these vulnerable people are not put on the food ration, they have difficulties finding a family or a person who will cook for them. They need that food so that another family can support them". Although Mohammed's family also used produce from their own field to take care of Rafael, his food aid seemed to be a welcome contribution to their household. While I often heard and observed that people were generally willing and ready to help disabled people in Kyangwali, I argue that longer-term care engagements were – at least partly – motivated by the aid that disabled people received (see more on this issue in Chapter 4).

7 Conclusion

This chapter has highlighted the mismatch between Uganda's policy of self-reliance and food aid as a means of survival. The WFP's provision of food aid did not truly compensate for disabled people's exclusion from the self-reliance strategy. Hence, my interlocutors felt unjustly treated in this situation and complained that "the food is not enough". In their view, food aid should also enable them to become self-reliant and to support their families, which is why they questioned the existing logic of food distribution.

The vulnerability criteria that entitled disabled people to special food aid were based on their compromised access to food due to their inability to pursue agriculture and a lack of social support to do so. With this focus on social support, the EVI criteria pushed disabled people to be dependent on their family and community. The criteria not only failed to fulfil their proclaimed purpose of compensating for people's identified vulnerabilities in terms of inequality and dependence, but even bore the risk of widening the gap between those who were dependent, and those who were able to provide. The recognition through the EVI criteria turned out to be disappointing for my interlocutors in this regard.

Food aid nevertheless became an important part of people's socialities, when they shared, exchanged and contributed food aid within their social networks. Food aid could help disabled people to create and maintain social connections – an endeavour that was especially relevant in the refugee camp, as the situation in Congo and displacement had often led to ruptures within them. In this way, instead of creating dependency, food aid could make disabled people more independent within their social networks. Yet also, instead of bringing about the withdrawal of family or community support, food aid enabled disabled people to be more easily helped with cooking, fetching water or collecting firewood, especially as it provided an amount of reliability in a context of uncertainty.

CHAPTER 3

More than Having a Roof over One's Head

1 Case 3: Muriel

A newborn, alcohol and a broken wheelchair

As always when I visited Muriel, we sat in the shadow of a simple shelter in their compound. Someone had replaced the shelter's missing rooftop with old cloth rags, to provide some shade from the blazing sun. Just a week ago, Muriel had given birth to a daughter called Naomi. Aged 32, she had eight children, but Naomi was the first to come into the world in the refugee settlement. Muriel's other children had been born before her family fled their home country of Congo when the Ugandan rebel army, the Allied Democratic Forces (ADF), attacked the town of Kamango and forced ten thousand refugees to flee to Uganda. Muriel got separated from two of her children during this incident and had not yet found them. While we talked about the birth of her daughter and the upcoming needs for the baby to grow up safe and healthy, Muriel began expressing her dissatisfaction that, in Kyangwali, not everyone with a disability was treated as such.

Muriel's legs had been paralyzed since she was affected by polio in childhood. She moved around her home by crawling, and for longer distances someone from her family usually pushed her in a wheelchair she had received in Congo from the 'Free Wheelchair Mission'. But the tyres of this wheelchair were completely broken, and Muriel was waiting to have it replaced with a tricycle from the service providers in Kyangwali. As she had been assessed for, and promised, a tricycle by the aid organizations a long time ago, she was irritated that she had not yet received one. Muriel started to compare herself to her neighbour Jacob, who had also been disabled since childhood by polio. She complained that the aid organizations had not only supplied him with a tricycle already, but had also built a new house for him – one with bricks and a corrugated iron roof. Muriel herself, in contrast, had been allocated quite a different house by the camp authorities. Mud fell out of its lopsided walls, the grass-thatched roof leaked, and the door was broken.

This situation left Muriel puzzling about why she had not received the same support as her neighbour. I knew from aid workers that she did not fit the eligibility criteria for shelter construction because she had an able-bodied husband who was expected to build a hut for the family. When I shared this information with her, Muriel disagreed with that reasoning:

> My husband cannot do everything because he is busy working elsewhere, moving up and down, so that our children can have food. It is not easy for him to find time and start building. Now, why did they construct a house for Jacob [her neighbour] and yet he has a wife? And Jacob has a lot of strength, he is not like me.

Muriel not only contrasted her treatment with that of a neighbour who had a similar disability to her, but her bewilderment also resulted from another comparison, when she inquired: "So why were they [the aid agencies] back then building houses for those that had husbands?" Muriel was referring to the time she had arrived in the settlement two years earlier, in July 2013, when she and her family were given shelter in a place that came to be named 'PSN Street' by the aid workers. As an emergency response to the deteriorating security situation in Eastern Congo and the consequent sharp rise in the number of Congolese people seeking safety in Uganda at that time, the NGO Nordic Refugee Relief (NRR) had constructed a large number of huts for people with injuries and disabilities, orphans, elderly people and single mothers in a certain location in Kyangwali. Muriel had benefited from one of the many huts which the aid organization had built specifically for people they identified under the administrative category PSN (person with specific needs). She told me that, after this first home in Kyangwali had been destroyed by the wind, she and her family were given the opportunity to reside in a vacant house in their current location. When I asked if she had approached the service providers with her concerns, she replied:

> I have done so many times. I have complained to them concerning a house, I have complained to them about a pit latrine, I have nagged them for support with a tricycle. I have not got a single thing. Every day, they [the service providers] hold meetings which I also attend, but I have not got anything meaningful out of them.

Muriel explained that she had reported these issues to the community social worker several times, and wondered why she had not been helped as expected. As she had not even received any response from the community social worker, she had concluded that, "the community social workers are just filling their own stomachs, not ours".

Muriel expressed her desire for a decent house, but also for a pit latrine and a tricycle on many other occasions. She was not alone in raising these issues. When I visited Muriel, especially in the afternoons, I often found a bunch of other people underneath the shelter. They sat on the wooden benches and chairs, drank liquor from small glasses and *kaveras*, the small plastic sachets that you had to bite open to enjoy the alcohol. They were happy that I usually shared some Sportsman with them, which was the more expensive brand of cigarettes you could find in Kyangwali. Most of these people were Muriel's relatives, for example her paternal uncle, his daughter and her children, and other brothers from her father's side, but some neighbours also joined in. They all frequently complained about the unfair treatment given to people with disabilities, including me in their demands by pointing at Muriel's broken wheelchair and inquiring if I could help her get a new tricycle, or asking me to buy them more alcohol.

Muriel and her husband Kenny served alcohol not only in their compound, but also at the weekly market in the nearby village, where they usually rented a shelter to sell their product. On one of the days I visited them, Muriel had sat on a small chair in front of a table, her heavily pregnant belly covered in a colourful *kitenge*. She constantly poured the home-brewed colourless but strong spirit out of a big plastic bottle into small glass cups which were shared among her customers, mostly young men, but also some elderly people, including women. While Muriel was busy serving, collecting money and selling individual cigarettes out of a packet, Kenny helped Muriel to pour more of the alcohol out of a jerry can into her plastic bottle, or left to find smaller change money. It was also usually under Muriel's guidance that Kenny and their oldest daughter Kansiime – who attended the fourth class in the village primary school – helped to bathe the younger children, prepare food, wash clothes in the nearby river, or carry the baby from one place to another. When Muriel talked one day about Kenny's role of providing for her and taking care of their children, she described his importance in her life as: "He is my strength".

2 Case 4: Jacob

Mobile phones, bride wealth and school fees

Even before I met Jacob for the first time in Kyangwali, I had read about him in an online article on the UNHCR's website. The article described how Jacob, whose legs were paralyzed by polio in childhood, had reopened his business repairing cell phones and radios in Bubukwanga transit centre at the Ugandan border just hours after his arrival. I was quite excited when a social worker from the NGO Africa Help Mission (AHM) mentioned his name during my first visit to Kyangwali in 2014.

Once in Kyangwali, Jacob had again started his electronics repair business, which entailed placing a small table in front of his house and waiting for customers. While he was fixing phones and other electronics, his wife Rehema usually handed him different gadgets, or lit the charcoal stove to heat his soldering iron. Rehema was Jacob's second wife. He was already married in his hometown in Congo but, like Muriel, he had fled Kamango due to the activities of the ADF. His first wife, with whom he had five children, had crossed the border with him but soon went back to her home and since then had never followed Jacob and their children to Kyangwali. Jacob had once mentioned that he was not surprised about this, as her family had never been happy that she had married a person with a disability. Jacob quickly wanted to remarry, as he needed help with his business, and with household chores like fetching water, cleaning and cooking.

One day when I was visiting Jacob, it threatened to rain, so we moved into his hut. Clothes and sheets hung on several lines under the roof. On one wall was a family photograph, and next to the entrance a small table and closet packed with pencils, body creams, pills in small plastic containers, nail polish, and various papers. Although built in the same style as most huts in Kyangwali, Jacob's home was definitely one of the more prosperous I visited – not in regard to its size, but due to the belongings kept inside. For example, Jacob owned a small DVD player on which he played video clips of Muslim music. When we talked that day in Jacob's house, he told us: "People with disabilities are suffering a lot. They are not getting any special support. The people from the offices are eating money". Statements like these were very common in all our conversations. Jacob was convinced it was not the case that the aid agencies lacked funds, asserting that: "There is a lot of money, but they don't want to give it out". Jacob had fled Congo with an old wheelchair, so he had spent a lot of effort in acquiring a tricycle from the aid organizations. As it had taken several months until he finally received this made-to-measure device, Jacob often expressed feelings of anger towards the service providers' careless attitude.

Like Muriel, Jacob was allocated one of the huts specifically built for 'persons with specific needs' in the so-called PSN Street when he had arrived. That area was a long way from the settlement's centre, so his distant relative Isaac had offered Jacob an empty hut in his compound when the previous owners decided to return to Congo. At one point, however, a conflict had affected the relationship between Jacob and Isaac. As village chairman, Isaac used his authority to allocate Jacob's initial – but by then vacant – plot of land to other refugees. I learnt about this incident when I visited Jacob some months later in his new place near Muriel's home, where he had been allocated a house similar to hers by the aid agencies after leaving Isaac's compound due to their conflict. Jacob had just returned from a visit to Rehema's family near Kamango in Congo, where he had handed over Rehema's bride wealth of goats. He showed me the 'road permission' he had acquired from the camp authority, a document that allowed him to visit another Ugandan district for five days. Of course the camp authorities would not allow him to travel to Congo, but crossing the border was not very difficult once you had permission to leave the settlement for a certain number of days, he explained with a mischievous smile.

When I visited Jacob again several months later on in my fieldwork, I was not surprised to find his old hut replaced by a new brick house with a corrugated iron roof, since Muriel had already told me that the aid agencies had built him a new house. Jacob sat on a bench and played with his small, paralyzed legs while he talked about his current situation. He was worrying about paying his children's school fees before they started their exams. They attended a boarding school outside the settlement, and Jacob usually managed to cover their school fees with the money he earned through his entrepreneurial skills. Although he did not have the full amount at hand, he nevertheless wanted to go to the Mobile Money centre in the nearby village to send at least part of the money to the school. Rehema placed the tricycle at a right angle so that Jacob could climb into it from the wheelchair, which he normally used to manoeuvre around the house. I followed Jacob on my bicycle, admiring the new green and white adornment of the Muslim moon and star symbol on the back of his tricycle seat.

⁖

Once people arrived in Kyangwali, the aid agencies gave them tools and materials to build their own homesteads on the land allocated to them. They received a machete to clear bushes off the land if necessary, they were given poles to form the structure of their future huts, a shovel to dig holes in which to insert the poles, as well as a tarpaulin to act as an instant roof. With the help of these items, refugees built their huts from walls out of reeds and mud, and replaced the tarpaulin with a grass-thatched roof, or even with corrugated iron sheets. People who were identified as vulnerable in terms of shelter construction received assistance upon arrival, as had been the case for Muriel and Jacob. They were both given a shelter in a place that had a number of already-built huts. Yet, their stories raise questions around access to shelter, as well as other forms of assistance. Like Muriel, the reader might wonder why the aid agencies had built a new house for Jacob, but did not give Muriel the same support.

This chapter takes as its point of departure the observation that being categorized in the same way did not necessarily lead to gaining equal support. In Kyangwali, a standardized categorization system with defined criteria guided the distribution of aid. Yet, mutually dependent relations between the beneficiaries, the service providers and their donors thoroughly shaped this seemingly transparent aid distribution. This chapter focuses on this co-existence of networks of patronage and bureaucratic standards to delineate what kind of relations unfolded in this situation. It is thus not just about shelter in the sense of a having roof over one's head. It is also about other forms of help and about finding refuge and long-term protection through relations of patronage. The concept of 'clientship' developed by Whyte et al. in regard to HIV/AIDS treatment in Uganda is useful for exposing the nature of these relations, as it pays attention to what is practiced and exchanged, based on certain moral logics within these relationships (2014, 56 ff.). Building on this concept, I will show in this chapter that the more charitable forms of assistance in a refugee settlement are also acts of exchange within relationships of mutual dependence over time.

First, I will look at the interdependent relations among the aid agencies and their donors by focusing on donations and the dynamics they entailed in shaping – or often, rather, blurring – the criteria of the seemingly clear-cut categories. This situation left disabled people perplexed, as they personally observed how entitlement to benefits varied – often quite ambiguously in their view. Yet, this situation also allowed for comparisons to be made, which provided crucial grounds for people's sense of entitlement and the way they made claims.

Muriel and Jacob's stories also revealed their disappointment in the services provided. They felt disappointed, not only in comparison to what others received or to what they themselves had been given at different points in time, but also because they had constantly shared their concerns and given information in their interactions with the aid agencies. They were assessed for services and items like a tricycle but were forced to wait for them for a long time, or had not yet been given one. The omnipresent paperwork – registration forms, needs assessments, reports – implied recognition, thereby raising people's hopes and expectations. However, they were then frequently let down, when the anticipated support was not forthcoming due to limited budgets and donor preferences.

Despite these bureaucratic procedures, disabled people experienced their access to aid as a very personal issue. They were in contact with the community social workers or other aid workers that administered the categories, conducted interviews or carried out assessments. Together with the fact that aid allocated through the categorizations was a somewhat uncertain and flexible process, this situation provided a breeding ground for mistrust. I therefore argue in this chapter that, instead of providing transparency, the aid agencies' working procedures of delivering aid along categories actually raised disabled people's suspicions that the aid workers were not performing their jobs faithfully. All of these factors point to certain moralities of exchange, and to expectations and questions of accountability that shaped the complex relations between beneficiaries, the service providers and their donors.

3 Dynamics of Donations

When Muriel and Jacob arrived in Kyangwali, they had both benefited from the large budget for shelter construction which the aid organizations had available at that time. With the start of heavy fighting in North Kivu between the Congolese governmental army and the M23 rebel group (*movement du 23 mars*) in 2012, and especially with the recurrence of the ADF's activities, the UNHCR and the Ugandan government had launched an emergency response in 2013. At that time, an average of 2,400 refugees were entering Uganda each month. Most of them were relocated from the Bubukwanga transit centre to the Kyangwali refugee settlement, and the appeal for emergency funds covered these two locations (UNHCR 2013). The Nordic Refugee Relief (NRR) and Africa Help Mission (AHM) had built 123 huts for people deemed vulnerable in the budgetary year of 2013. However, the situation in Kyangwali during my fieldwork was no longer deemed an emergency, so the budget had been drastically reduced to cover hut building for between 10 to 30 people who were categorized as PSN per year (by 2016 only AHM was responsible for shelter construction).

This reduction in money demanded identifying the most deserving recipients. One of the aid workers told me how they dealt with such limited funds: "You have to decide: who needs what most? A hut is now 1.4 million Ugandan shillings,[1] these new ones we build with bricks. So you have to prioritize. The money is not enough, but the beneficiaries are many". This aid worker also referred to the new standards for constructing huts for 'vulnerable' people, which the UNHCR had introduced in 2016. These houses had to be built out of bricks and topped with iron sheeting, instead of mud walls and grass-thatched roofs as in earlier times. The cost of these increased standards had also impacted on the reduced number of beneficiaries. The fact that "the money is not enough, but the beneficiaries are many" had its roots in the specificities of

---

[1] Approximately 385 US dollars.

hierarchically ordered vulnerability categories. An independent study on the function of community services within the UNHCR states that:

> Due to a scarcity of resources (in the form of food, non-food items, cash or in-kind assistance) the institutional response has been to further and further reduce the numbers of those who are provided with any form of additional assistance based on their vulnerability. What was originally a focus on vulnerable groups or groups with special needs so as to ensure programmes are accessible and inclusive, and thus to design programmes which meet the needs of all refugees, has frequently been subverted during budget crunches. Instead, the keeping of lists of "vulnerables" becomes the basis for various types of "hair-splitting" machinations, to identify Extremely Vulnerable Individuals (EVIS) or the really, really very vulnerable.
>
> UNHCR 2003, 33–34

The fact that most of the UNHCR's funding originated from donors was evident in everyday life in the camp, where food packaging, mosquito nets, mattresses and buildings were labelled with 'donation by', for example 'The Government of Japan', 'The American People', or 'Aid Global'. Uganda's current refugee policy was tightly bound to this dependence on donors. Uganda would not have the capacity to provide its rather generous refugee assistance on its own terms.[2] Glasman describes how, with the UNHCR's growing presence in the Great Lakes region, African governments could only be convinced to accept refugees as long as most of the assistance was provided by Western donors (2017, 9).[3] This dependency on donors not only critically shaped the availability of funds, but also the aid agencies' criteria and ranking of beneficiaries. An aid worker told me:

> When we receive donations, for example clothes, the donor states precisely which group of people they are for. So even if there is a distribution

---

[2] In a summit in Kampala in June 2017, Ugandan president Yoweri Museveni and the UN secretary general António Guterres announced that Uganda's refugee response would require 674 million US dollars. In August that same year, only 20 percent of that money had been raised, which brought about a critical situation for the South Sudanese refugee response in and around the camps in Northern Uganda (Okiror 2017).

[3] The current refugee policy is thus not unfavourable for the Ugandan government, not only because they receive a lot of external support (in 2002, Harrell-Bond revealed that the salaries of staff in the Office of the Prime Minister (OPM) had been topped up with contributions from the UNHCR, for example (Harrell-Bond 2002, 24)) but also as, according to the ReHope strategy, 30 percent of humanitarian support should go to the host community.

> for EVIs, it still depends if you will get something or not. The donors sometimes want their donations to be distributed to specific groups of people; maybe children with disabilities, but not all EVIs. So they decide on their donations, and people will complain: 'Why not me?' But we cannot go around the donors' stipulation.

While people in Kyangwali were informed that the ones identified as 'extremely vulnerable individuals' (EVIs) should always be given priority, support apart from food assistance was often channelled along specific PSN categories. It targeted certain groups of people, as instructed by the donors, or as part of the UNHCR's strategy to deal with the limited funds available.

In such a manner, the eligibility criteria for hut construction had to be redefined as a result of budgetary constraints the service providers experienced after the emergency situation in 2013. I learnt about this when I had the opportunity to accompany an assessment for hut construction exercise. I joined a team of representatives from the UNHCR, the OPM and the AHM who drove from village to village in order to visit potential beneficiaries. The community social workers from the respective villages had identified the potential beneficiaries beforehand, according to the current year's criteria for hut construction, which targeted people who were either elderly or had disabilities. While we went from hut to hut, the officers not only inspected the condition of the dwellings, but also verified whether the candidates actually fulfilled the criteria. The eligibility criteria did not seem to be very clear to some of the community social workers: one of the aid workers went through the prepared lists of potential beneficiaries and crossed out all the people designated as 'single mother' or 'unaccompanied minor'. Although they were categorized as vulnerable under the PSN category and, in principle, could be considered eligible for hut construction, a number of people were not able to benefit from this specific support due to the limited funds and the modified criteria. This situation left community social workers and people with disabilities alike confused.

The fact that certain categories of people were deemed deserving at different times, and that sub-categories of 'vulnerable' people were targeted selectively, contributed considerably to disabled people's incomprehension of how aid was distributed. The new standards for constructing huts for 'vulnerable' people even added to the resentment of the many people who were not able to gain access to one of the new brick houses. I approach these experiences as being historically contingent, since the categories, their criteria, and the aid that was channelled through them was not completely rigid, but was shaped by donations and thus by dynamics which could not be influenced by personal connections (Whyte and Siu 2015). Yet, despite the dependencies on donations and their associated criteria, people in Kyangwali were not merely passive receivers of aid. Their puzzlement also served as productive grounds on which to challenge the logics and practices of distribution and to negotiate individual benefits in their personal relationships with aid workers.

4 Comparative Benefits: Sense of Entitlement and Claim-Making

Women in the camp were not expected to take on responsibility for constructing a hut in the same way that men were. Jacob and Muriel were both considered physically vulnerable but Jacob, who had a wife, was eligible for institutional support for this, whereas Muriel's husband was supposed to take on the construction work. One of the aid workers explained the organization's expectations from men with regard to construction: "It is because it is not considered a woman's role. Women have never learnt to build, so it is the man who has to construct the house". In this sense, the criteria for hut construction were highly gendered, as they assumed women to be dependent on their husbands. Through these gendered logics and practices of distribution, specific kinds of vulnerabilities were again recognized, while others were not (see Chapter 2). It is worth noting that, in the cases discussed here, conventional gender roles were only enforced through the categorizations when funding was cut and the criteria had to be amended. It was therefore not surprising that Muriel questioned these gendered logics of distribution, as she had observed how the aid agencies had formerly built a home for her and other women with husbands.

She explained that, in Congo, aid agencies had previously built her a hut because of her disability. To be categorized as vulnerable and therefore eligible for specific support was thus nothing new for Muriel. Her expectations were again confirmed when the aid agencies had allocated her a hut upon arriving in Kyangwali. Considering these previous services, Muriel was understandably puzzled when she abruptly stopped receiving this support, even though she still needed it. Her claims for support were anchored in her past experiences, but also in what she recounted had been more comprehensive assistance in Eastern Congo: "In Congo I was well, because there I would receive everything. They [referring to aid organizations] would announce the days on which they would distribute clothes or wheelchairs, and you would receive them. All the disabled people would receive them. But all this, I have not seen it here [in Kyangwali]".

Ramah McKay observed similar situations among former Mozambican refugees who had returned to their homeland. She demonstrated how "humanitarian pasts" created new possibilities for claim-making, since they were contrasted with the "inadequacies of the present": "[C]laims to support are imagined and articulated not through discourses of the state, rights, or national citizenship, but through reference to a humanitarian past" (2012, 288–89). When disabled people complained about the scarce assistance they received in Kyangwali, they often compared it with better disability assistance in Congo. They told me about the government's tax exemption for disabled people who engaged in border trade (see also Devlieger 2018a),[4] and talked about foldable and motorized tricycles, or recalled that they could simply call someone to come and repair their wheelchairs. The notion of: "Whatever you asked for as support, they would give you", as one woman with a disability expressed it, resonated with much of how disabled people made claims by invoking a better humanitarian past.

When Muriel questioned the eligibility criteria for hut construction, she was not only comparing her current situation with what she had experienced in the past, but also with what was playing out right under her nose, when she contrasted her situation to Jacob's. The channelling of aid along certain categories of people strengthened this comparative basis, especially as people often lived in close proximity to each other and so could observe what others received. Another disabled woman I knew similarly expressed her view of the fact that the organizations did not build her a new hut after her house had burnt down:

> How do they really expect me to build, me, a vulnerable person? At the office they gave me poles, but they thought those poles would be enough without a roof on that house. They just said: "Get the poles, your husband is strong and will build for you". I answered: "Yes, my husband is strong, but what can one hand [one person] do alone? Can you not support me and help me the way you help others? You always help other women who have children [referring to single mothers]. These women have both hands and legs, but me, I am just alone with my husband".

Here, the woman compared herself with 'single mothers', another administrative category among 'people with special needs', who were able-bodied but perceived as vulnerable in relation to shelter construction, based on the gendered criteria. By explaining that, "these women have both hands and legs, but me, I am just alone with my husband", she was arguing that having a husband

---

[4] During a visit to the city of Goma, the capital of the Eastern Congolese region North Kivu, I got a glimpse of this border trade with Rwanda at the so-called '*petite barrière*' in the northern part of the city. With broad tyres and steering wheels, the tricycles used for this border trade were specifically designed to carry heavy loads.

should not be perceived as balancing out her lost limbs. People with disabilities thought it was especially problematic when other 'vulnerable' people, like those with HIV/AIDS, received more support than they did. For example, Camille (case 6) made the comparison: "People with disabilities are not given anything. Yet, those with chronic diseases like AIDS are the ones who are supported".[5]

Muriel's complaint about her own housing situation compared to her neighbour's, that "not all people with disabilities are treated as such", could refer both to a belief that they were not being treated equally the way they should be, or that they were not being treated the way they rightfully deserved. Stone portrays the notion that disability is a state of being that deserves special aid (1986, 26) as a historically-evolved assumption of the welfare state. Yet the omnipresent comparisons with the benefits of other people, times and places which my interlocutors complained about and which they based their claims on pointed to a different trajectory of how people with disabilities in Kyangwali came to perceive themselves as being entitled to special aid within the refugee regime. Eckert approaches citizenship as something fundamentally social that develops in interaction and in comparison with others, as she argues: "[t]he understanding of rights and the perception of oneself as a rights-bearing subject emerge in social relations, collectively with others or by comparison to others, and by recognizing the similarities in forms of subjection and in the needs of life" (2011, 313). The way that disabled people in Kyangwali made claims showed how their senses of entitlement had developed through what they experienced over time and in everyday encounters in Kyangwali.

In contrast to what has been yielded from many discussions of biomedical or therapeutic citizenship (e.g. Biehl 2004, 2007; Nguyen 2010), my interlocutors' claims and complaints did not seem to be connected to an international rights framework. 'Comparative benefits', which entail both people's senses of entitlement and ways of claim-making, qualify the relevance of a reference to universal human rights, but highlight experience and practice on a very personal level. Thinking about what they had received before or what benefits their neighbours were given was more readily available and meaningful for my interlocutors than thinking or talking about abstract human rights. In fact, people's senses of entitlement derived from experiencing and comparing

---

[5] During my fieldwork, people living with HIV/AIDS were automatically considered in the highest category of 'vulnerable' people. Therefore, they were handled differently to disabled people, for whom family constellation and support structures could be excluding factors for food aid, for example. Aid workers explained that people living with HIV/AIDS were automatically considered in the EVI category because of the medication they were supposed to take with food.

situations of aid provision and the social relations that came into play within these interactions.

Whyte et al. developed the concept of clientship as distinguished from citizenship, as it emphasizes the personal and social in relations of interdependence, which can specifically be investigated in terms of exchange (2014, 62). Rather than focusing on more abstract entitlements given through rights and recognition, the concept of clientship examines what is actually traded in the relationships between programmes and people (58). In the next section, I will analyze what was exchanged in Kyangwali between beneficiaries, aid agencies and their donors through paperwork – a domain where the entanglement of relations of patronage and bureaucratic procedures became especially apparent.

5 Disappointed Recognition: "Just Writing, Nothing Else"

Anette held the youngest of her six children in her lap while she cooked beans in a pot over a small open fire in the middle of a shelter in their compound. We talked about her relations with aid workers, and she explained: "They just come and register us, they are writing reports, but there is no value for a disabled person in this". While Amani translated these words to me, Anette mumbled in the background: "Just writing, nothing else". Decrying the relief agencies' work as "just writing, nothing else" entailed a critique that pointed to a larger issue than merely one of individual concern to receive aid. Paperwork was an integral part of the aid organizations' working procedures in Kyangwali: assessments, reports and project descriptions were all necessary documents for receiving funds, for aid to be distributed and for accounting to donors. It was thus a crucial component in the interdependent relations between disabled people, the service providers and their donors, but one which led to undesirable effects on "the ones being written about" (Whyte 2011, 29), especially as their sense of a morality of exchange was not being fulfilled.

As the tool through which relations with the aid agencies were mediated, paperwork often implied possibilities that were created in relation to people of power and authority (Whyte 2011, 43). In the context of writing within medical research, Whyte argues that, through the act of writing, "respect and recognition are being expressed and mediated" (2011, 49). Likewise, having their names and requests written down made disabled people in Kyangwali believe that their concerns were being recognized and would be acted on by the service providers. As Mansanga (case 1) explained:

> I always go there [to the next bigger village, where assessments were often made], they record and take information. We are always in meetings, those concerned with the disabled. I always take part in our programmes, but nothing, there is no response. They register me, but things fail. They register me and take my name so that I will get things, but nothing!

Mansanga's son Benjamin added: "Even the social worker comes every day and asks for her ration card, he also writes. But nothing, they just keep on only writing". The fact that Mansanga had been registered, that her name was taken, that she gave information and showed her documents, implied that her concerns were being taken into account and would be met. This expectation was dashed by the lack of subsequent activity. While people were constantly being assessed, but ultimately not supported in the ways they had expected or hoped for, these acts of writing had become more about disappointment than acknowledgement.

Especially keeping records of people over time, as Whyte et al. observed within antiretroviral treatment programmes in Uganda, signifies a long-term commitment (2014, 56–59). Similarly, the UNHCR's paperwork in the refugee camp seemed to suggest an obligation to protect people and provide specific services in the long run. From the day someone crossed the border into the country, the UNHCR and its partner organizations collected and stored their data. People had usually already been registered in the transit camps at the border, where "files are opened which move with them to where they are settled", as an aid worker explained. People were biometrically registered, their fingerprints and pictures taken. This information was, on the one hand, included in the various databases (the UNHCR's ProGres and the OPM's RIMS) while, on the other hand, it was printed on the refugee attestation cards that included names, pictures, ages and date of arrival of members of a household. Many people I interacted with in Kyangwali wondered why they were being neglected, yet they knew they were supported by the UNHCR – a relationship that had been initiated by this very formal act of registration.

The act of writing not only raised expectations but, through paperwork, certain information was eventually exchanged for money and resources (see also Whyte 2014, 45). For any kind of aid to be delivered, people had to get involved in paperwork – they had to show their identification papers, and also had to give their signature or thumbprint. These acts were part of the reporting and accounting machinery of humanitarian aid, one that predominantly represented a one-directional flow of paperwork, and thus accountability, towards donors. When I observed a clothes distribution session in one of the settlement's villages one day, it took me a while to figure out how the procedure worked. Aid workers in plastic chairs processed the distribution, attending to the refugees who had gathered and were queuing up in several lines. People firstly had to line up to receive a slip of paper with their serial number on for that distribution session. Next, they waited to be verified; they again had to show their attestation cards, and sign or give a thumbprint on another sheet of paper that was kept by the distributing organizations. From there they had to line up again for the actual clothes distribution. There, they had to present their attestation card and slip of paper, the serial number which referred to a list that signified the number, age and sex of their family members. Reading from this list, the aid workers knew how many trousers, shirts and shoes they had to give out.

When I inquired about this process of distributing clothes, an aid worker explained: "This is just for accountability purposes, nothing more. Because how does an aid worker account for the items he has requested from the office? The last beneficiary has to append a signature or a thumbprint that he or she received it. It's simply for accountability purposes". Signatures were needed for the organizations' reporting to their donors: counting how many people they had given aid to meant accounting for the organization's success. A 2014 report from the organization Africa Help Mission (AHM) listed the following account of specific services they had provided to people with disabilities:

- 5 PWDs [people with disabilities] supported to establish functional gardens measuring 40 × 50 metres; seeds procured, i.e. maize and beans, supported in planting and harvesting. This intervention has enhanced their dietary diversity.
- 40 (M26, F14) PWDs assessed and supported with mobility appliances, which has improved their mobility and thus improved self-reliance.
- 293 home visits to 183 (M96, F87) PWDs conducted and psychosocial support ensured.
- 50 (M25, F25) PWDs identified for training in making handicrafts.[6]

Organizations must provide evidence that they are doing their jobs well, meaning they have to collect a vast amount of paperwork (Whyte et al. 2014, 64). NGOs and UN organizations rely on formal records that document their activities for accountability purposes – and numbers in particular are aggregated into reports.[7]

---

[6] Africa Help Mission (AHM), PWD Report, document received in Kyangwali in April 2014.

[7] Evaluations of these reporting formats have pointed out the limitations of measuring aid organizations' performance in terms of what assistance they have given to how many individuals, which does not count the people whose needs were not met (Bakewell 2003, 13–15; UNHCR 2003, 27).

As for the clothes distribution described above – for any kind of aid distribution – people had to line up, follow the specific procedures and bring all the required documents, but most of all, they had to wait, sometimes for hours and hours on end. They had to be physically present for assessments and in meetings, in order to sign, and thus to be counted. Time was what people exchanged when they were giving information in order to access resources. It was what the organizations relied on for the paperwork they required for their own exchange relations with their donors. The fact that these exchange relations between donors and beneficiaries took place on unequal terms was apparent by the way that the recipients had to accept and submit to the providers' rules, conditions and given procedures. However, when people's senses of a certain morality of exchange in these processes was not responded to appropriately, they often became suspicious and dismissive, as expressed by one of my interlocutors: "Here they don't build for people! Nothing! For them it is just to give reports, they don't even help people". Changes in the criteria and categories, combined with these processes of paperwork, created a virulent breeding ground of mistrust, which I will discuss in the next section.

6 Mistrust and the 'Good' Beneficiary

Mistrust towards service providers was a common attitude in Ugandan refugee camps, and in East Africa more widely. Accounts that aid representatives were "thieves" who were "eating money" and then "cooking stories" in order to obscure their misuse of money were prevalent around many institutions that provided access to resources. Muriel expressed her mistrust towards the service providers when she talked about how many times she had raised her complaints to them, and yet nothing had resulted from it. Elaborating more on this issue, she explained: "I think that sometimes those who come to register us, maybe they don't take all our complaints to the office. They come and tell you to sign, and when you sign, they go the next day [to the office] to show that the support was delivered. Yet, we did not receive the support!" The mistrust that arose through this practice of signing was also because Muriel did not know how to read and write, as she said: "He asks me my name, I tell him, and he writes. Then he says, 'bring your hand, sign here', but maybe you have no reason to sign".

Certainly, my interlocutors' relations with people at different levels of service provision were diverse. While some aid workers and community social workers were perceived as being helpful and caring, others were described as rude and indifferent. But often when my interlocutors did not receive what they believed they were entitled to, they were quick to conclude that the system and its workers were corrupt. Recounted incidences of corruption went as far as scholarships being given to aid workers' relatives, clothes from a distribution session being sold at the market, or goats which were supposed to be providing livelihood support for 'vulnerable' people being spotted among Ugandans in the neighbouring villages. Drawing on what other anthropologists have observed about mistrust towards service providers in African contexts (Swidler 2009; Voutira and Harrell-Bond 1995; Whyte et al. 2014; Whyte and Siu 2015), I point out the specificities of mistrust in a refugee settlement. Mistrust not only played a role for the people who received aid, but aid workers also commonly experienced and expressed mistrust towards their beneficiaries. Valentine Daniel and John Knudsen address this in the title of their edited book *Mistrusting Refugees*, which can be understood in the two ways that "the refugee mistrusts and is mistrusted" (1995, 1). This section considers a morality of exchange from both these viewpoints.

The way Muriel doubted the working ethics of the community social worker shows that suspicion was geared more towards specific people than any institution as a whole (see also Whyte and Siu 2015). Yet, despite mistrust being personalized, there were patterns in how some groups of people channelling access to resources were considered to be more trustworthy than others. For instance, there was much more mistrust towards Ugandan aid workers than towards foreign aid workers.[8] Muriel explained this in comparison to aid she had received in Congo: "There [in Congo], why it was possible for us [to receive support], was because the foreigners themselves would come. They would be the ones to deliver the support and distribute it to the disabled. But here, if they give support and say, 'go and give it to the disabled', we cannot get it".

One day I witnessed the different understandings and expectations that had evolved around the role of a community social worker. I visited Daniel, who had been bedridden since severely breaking his hip in a motorcycle accident. He made accusations against his community social worker:

> He came to register me in the book for all the disabled. They took them [the names] there, where they always take them, to the whites. By the time my name appeared, he plucked it out, he put it aside so that my name did not appear. All the others, their names came out well, there is no one that was missing on the list. So I wondered, which type of parent is this? He is the one who ate [deleted] my name, he has eaten my name.

---

[8] The fact that foreign aid workers were more trusted was also observed, for example, among Congolese refugees in Tanzania (Thomson 2012, 187).

At one point Daniel felt that the community social worker should join our conversation. When he reached the house after Daniel had sent for him, he continued accusing him directly in front of us. The community worker defended himself by explaining: "You people do not understand our work. I have the details of your life in the books. The whole of your life is on the paper. For me, my role is to report, I just report". This revealed the contested position of both the community social workers and the aid workers. They had to register people, but all decisions about aid provision were made at a higher level. Swidler writes about how local people become brokers who mediate between local communities and international donor organizations, often realizing support through patron-client ties (2009, 213; see also Smith 2004). Swidler explains that, in contexts of scarce resources, "the NGO (or the individual NGO worker) becomes a kind of patron to the local collaborator, who may in turn have clients of his or her own" (206). Likewise, community social workers in Kyangwali, through making lists of potential beneficiaries and applying for specific resources at the offices, can be understood as such brokers, who became patrons and dependents at the same time.

In their role, community social workers in Kyangwali were often accused of favouritism. During the hut assessments that I followed, an aid worker wondered why they were only visiting people who were in the centre of villages. He argued that there were huts in much worse conditions in other places and he thus suspected the community social worker of channelling resources towards the people she wanted to serve. There were also many complaints that the community social workers would not do their jobs properly unless the applicants gave them money or sex. Conversely, community social workers recounted that people tried to bribe them in order to receive certain services, stating that, while they followed protocol and procedures and stuck to the tedious bureaucratic processes, disabled people perceived them as being corrupt.

Whyte observes that, because so much is dependent on people's relations with health workers, patients do not feel able to openly challenge them, instead criticizing them behind their backs (2011, 46; see also Whyte and Siu 2015, 28). The situation of Daniel and his community social worker was different in this regard, as Daniel overtly expressed his criticism in his presence. I only observed a few instances where people were openly criticized, but disabled people regularly mentioned that they "went to complain". Moreover, aid workers described many situations when refugees had directly raised their complaints with them. This points towards a different "ethos of contingency" (Whyte and Siu 2015, 27) existing in a refugee settlement than in other settings. Rather than grinning and bearing it when dissatisfied with the aid provision, people in this unusual situation acted quite forthrightly.

This openly expressed mistrust and allegations of corruption again emphasized the limited significance of a universal rights framework as the basis of people's actual claim-making. Claims were instead made on moral grounds that reminded the service providers of the obligations they were supposed to fulfil as patrons.[9] This had an impact on the aid workers. Some felt emotionally challenged and morally questioned, feeling obliged to defend themselves. Scarlett, for example, explained:

> We know that the support is not enough, because our budget is limited. But the little support we give is not appreciated at all, this is why you always hear from people that they have not received any support. If I tell them I do not have support, they feel that they are being mistreated. For me, who always visits people and interacts with them, I get hurt that people do not appreciate it at all.

Aid workers found it enormously difficult that the bureaucratic procedures required them to make assessments and identify vulnerable individuals, even though the budget for additional assistance was extremely limited. As a way to counter people's mistrust they often brought up paperwork, as Daniel's community social worker did, in order to emphasize the accountability and transparency of their working procedures. But clientship is also about the expectations that service providers have towards their clients, and the disabled people's possibility of receiving aid was dependent on their relations with the service providers, in the way that they were expected to be 'good' beneficiaries.

It is a common phenomenon for aid organizations to try to shape people's behaviour on the ground (e.g. Swidler 2009, 198; Whyte et al. 2014, 63). As mentioned before, people in Kyangwali were obliged to be present at certain places at specific times, bring their documents, give information, line up the right way and follow the given procedures in order to receive aid. Being a 'good' beneficiary, however, was more than that. Differing from the more concrete exchange of things, some of the perceptions of refugees involved a rather abstract reciprocity in the form of general expectations about their commitment and

---

[9] The way Daniel had called the community social worker a "parent" implied that he saw him as being responsible for his well-being, an expected role that he was not, however, fulfilling in his eyes. Calling someone a 'parent' was a widespread way of asking them for help. As demands made on family are usually more coercive than those made on other people (Durham 1995, 123), invoking kin relations seemed to be a way to consolidate the service providers' assumed responsibilities.

behaviour, which could influence which programmes they could access or the way they continued receiving aid.

Generally, people in Kyangwali were not supposed to abuse the service providers' trust. Giving false information, or any kind of cheating was problematic for the aid workers. Yet, they felt it was very common behaviour, as one of the aid workers explained: "You know, refugees are very stubborn people, they always try to find ways to beat the system". Against such widely held assumptions that cheating was a prevalent characteristic of 'the refugee' (see also Daniel and Knudsen 1995; Zetter 1991), I only came across very few instances when people were somewhat proud of how they had, for example, managed to acquire the food ration cards and identification papers of people who had illegally returned to Congo, allowing them to access a considerable amount of food, or when they did not travel where their movement permit allowed them to. It was rather that they "did not want to do anything that could be perceived as manipulative", as Thomson observed among Congolese refugees in a Rwandan refugee camp (2012, 186).

During the hut assessment I observed how people were immediately deleted from the list of potential beneficiaries when the aid workers suspected them of giving misinformation. The aid workers asked what they called 'simple' questions about family, lengths of stay in a specific place or number of people living in a house. When the people did not give immediate answers or gave unclear or contradictory information, the aid workers left annoyed, shaking their heads, without any further explanation. These were the very severe consequences that ensued when aid workers felt they had been lied to.

The hut assessment also gave an insight into the fact that the service providers expected their beneficiaries to take care of the things they had been given. Referring to Muriel's case, an aid worker explained:

> In 2013 on arrival, we supported them with a hut, but the same family wants another hut in 2015 and yet there are many people with disabilities. Despite her husband being able-bodied, we then gave them a hut and a latrine, because they were going as a combination. But now you are saying I again need another hut, after throwing that one down when you shifted to another village?

While several recipients had told the community social workers that the huts did not last for long, the aid workers felt that people were not taking enough care of these shelters. It was not just Muriel's able-bodied husband, but also the fact that they had left their emergency hut in the 'PSN Street' behind, which had minimized her family's chance of receiving a new hut. Taking care of the aid they were given was thus closely linked to the expectation that refugees should be appreciative of what they received. An aid worker once explained: “It is very important to interact with them [the refugees], to counsel them so that they can understand and appreciate the little they get”. This raises an issue that I deem important. Whyte et al. discuss the professional component that the concept of clientship entails, stating that “the term [client] suggests a contractual relationship based on professional standards” (2014, 57). While a ‘patient’ is usually expected to be passive and quiet, a client is a user of professional services who has expectations about these services (57). A client is thus in a position to complain if she or he is not satisfied with the services provided. Humanitarian aid can be less perceived as a kind of professional service, but is much more located in the realm of charity. Thus, from the aid workers’ point of view, beneficiaries should have been grateful and appreciative of anything they received, instead of complaining about its inadequacy.

7 Conclusion

This chapter has revealed that access to aid was not simply guided by an applicant’s categorization, for instance as an EVI, but that the interdependent relations between various aid agencies, as well as the interactions between aid workers and beneficiaries, played a considerable role in deciding how aid was distributed. Whereas categorizations and their criteria for aid distribution should have resulted in the most fair and transparent distribution possible, in reality, the different working procedures used to assign categorizations raised suspicion among the refugees. The availability of funds and donors’ priority setting made the allocation of aid a matter of constant change, which at times did not make much sense to my interlocutors, and led to different interpretations of the guidelines by aid agency staff and community social workers.

The application of the concept of clientship in this chapter has not only helped to illuminate the hierarchical chains of support between the different service providers, but has also proved useful for examining the relationship between disabled people and service providers, especially as it focuses on what is being exchanged within these relations – both the tangible and the tacit aspects. This shows that humanitarian aid entails more than just receiving something once. It is, in fact, an act of exchange over time, in which the aid agencies continually rely on the beneficiaries’ cooperation – to follow the given procedures of aid distribution, to provide information and signatures and to be physically present – in order to keep the donor money flowing. When aid was distributed, one of the determining factors was also how ‘deserving’ a potential beneficiary was, and this was subjectively decided, based on how much they had already received previously, and how well they had looked after the aid they had been given.

The omnipresent processes of paperwork which these exchange relations were based on, however, often kept the applicants in a void. My interlocutors experienced some kind of acknowledgement in the way that this paperwork made their concerns constantly recognized by and visible to powerful organizations that were obviously connected to a world of wealthy donors. Yet, they were often disappointed when the services they were offered did not match their expectations. People's senses of entitlement and the ways they made claims derived from these interactions with aid workers, as well as through comparisons with what other people received, or what they had previously been given at other times and in other places. This suggests that there was a limited relevance of universal rights for their ways of claim-making and senses of entitlement. This was also evident when disabled people insisted on a certain morality of exchange, expressing their mistrust towards the aid workers as a way of reminding them to fulfil their obligations. This was grounded in a certain logic of distribution in which they perceived the aid agencies as their patrons. Their feelings of disappointment and mistrust therefore resulted from a mismatch between what they expected and what they experienced within these relationships.

PART 2

∴

CHAPTER 4

Care for "People Who Cannot Help Themselves"

1 Case 5: Vitali

Rehabilitation centres, a radio and ducks

The camp boundary was marked merely by an open wooden barrier and the momentarily abandoned tent of the police guard in charge when I left the settlement along a narrow path on a *boda boda* with Amani and a friend from my research project. Not far from that border we found Vitali in a spacious homestead, seated under a shelter surrounded by bunches of dried tobacco leaves which he was tying into bundles. His broad shoulders and upright posture contrasted with his wrinkled face and grey hair. Vitali admitted that it was exhausting work, especially at his age, 77.

Vitali had been taught how to make tobacco bundles by his father, who was a tobacco farmer in Burundi. As Vitali could not walk after he contracted polio, and with the school too far away to reach, his father decided that he, out of all his children, should be the one to learn this type of work. One day Vitali had heard about callipers, a technology of "putting metals plus shoes so that you can walk", and he dreamt of going to Uganda. Callipers were then being offered at the recently-reopened Mulago Hospital in Kampala. In the wake of Uganda's independence in the 1960s, Vitali travelled to Kampala and had the opportunity to participate in a training programme for vocational skills such as shoe and calliper making in the newly-opened Kireka rehabilitation centre. With his certificate and skills acquired from Kireka, Vitali had looked for work in the new rehabilitation centres throughout East Africa. He succeeded in places as far off as the Yombo rehabilitation centre in Dar es Salam, Gatagara rehabilitation centre in Rwanda, and the *Centre des Handicapés* in Goma, in Congo.[1]

Vitali's travels through East Africa were not only led by working opportunities, however, but many times also forced by the genocide, turmoil and wars in Rwanda, Congo and Burundi. The political situation in the Great Lakes region was close to his heart, and three times a day he listened to a radio programme in Swahili. Still seated under the shelter and bundling tobacco, at one o'clock on the dot Vitali switched his radio on and continued talking to us. He

---

[1] When I visited the *Centre des Handicapés de Virunga*, North-Kivu in Goma in December 2015, I was pleasantly surprised that one of the elder staff members recognized Vitali in a photo I took along from Kyangwali.

explained that this seasonal tobacco bundling work had enabled him to buy two more ducks for his small poultry farm, which he managed together with his friend Alex.

When Vitali had finished his seasonal work at the tobacco farmer's place around two months later, I visited him at his home. His one-room hut seemed untidy. The floor was covered with empty plastic bottles and dirty dishes, and in the middle the radio lay open with tools scattered around it. Rats had gnawed through its cables and Vitali was attempting to fix it, so far unsuccessfully. Next to a cluttered pile of various metal items were an empty plastic Waragi bottle, a Ugandan liquor, and empty Supermatch cigarette packages. Vitali's pale eyes and sunken cheeks made him look tired that day, and his breath smelled of alcohol. Although Vitali had converted to Islam after being Catholic for most of his life, he had not stopped his habit of drinking alcohol.

Vitali had initially been given a plot of land by the camp authority far away from the centre but, due to the rough streets, he was barely able to manoeuvre around there on his tricycle. When a Congolese woman he knew left for the US through the resettlement programme, she had handed her home over to him. The new place used to have an outside latrine but, as this was not convenient for him, members of the Muslim community had constructed a pit latrine attached to his hut. This small annex, which was separated by a cloth, also served as a shower, where Vitali was able to wash himself while sitting on top of a plastic chair, so that the water could drain off easily. He also managed to fetch water on his own, as there was usually someone at the borehole who could pump water for him.

After I had been sitting in Vitali's hut for a while, a small girl entered, put two covered pots of food on the floor, collected the dirty dishes and left without a word. I had met the girl, Goretti, before, sitting on the back of Vitali's tricycle somewhere in the village centre, bringing a pot of boiled potatoes or *posho* with beans to Vitali, but she was normally too shy to speak to me. Mama Goretti, the girl's mother, usually collected Vitali's food ration and cooked for him, but her family also took care of him in other ways, as she told me:

> When I see that he has not come out in the morning, I go and check on him … They [the children] know that when we cook, they are supposed to take [food] for him. Sometimes they go and disturb him and say "Grandpa, let us put you on the tricycle and move you around!" So they move him around or they sit down and start conversing.

Whenever Mama Goretti's family struggled to support Vitali, she contacted Lionel and Youssef, Vitali's grown-up nephews who lived and worked in

Kampala. They were able to send some money once in a while. Vitali had been surprised to meet his nephews in the camp when he arrived in Kyangwali. However, he was even more surprised when one of his own sons appeared in the refugee settlement in early 2015. He recounted that he had lost track of this son's pregnant mother when they were fleeing from Burundi. Although his son had also settled in the centre of Kyangwali like Vitali, I had barely met him, and Vitali rarely spoke about him. When I questioned him about other children, Vitali laughed and shook his head: "I left others in Congo. I can't count them now".

Vitali reasoned that, because he was friendly to people around him, they would assist him with small tasks like buying batteries for his radio, fixing his phone or helping him take his maize for grinding. Vitali had travelled widely, spoke many languages and remembered by name not only friends from long ago, but also aid workers he had been in contact with. He interpreted his communicative character by saying: "I got this disability from polio when I was one and a half years old. I have never walked with my legs. If I didn't know how to get along with people and make friends, I would be dead by now. That's how I survive and I still love to live with people".

After one of my visits, Vitali and I left his home together. His tricycle was already outside, and he pushed it little by little until it was in the right position. He then put a dry gnawed-off corncob from behind the door under one of the wheels to prevent it from moving. With a lot of effort from his arms and torso he manoeuvred himself onto the tricycle. We were about to visit members of Aid Global's drama group comprising people with disabilities. As chairman of the drama group, Vitali wanted to show them the photographs I had taken during a rehearsal. I left my bicycle behind so that I was able to push him when the road became uneven.

2 Case 6: Camille

New skills, tomatoes and the football coach

It was a busy market day with women touting wares such as tomatoes, onions or the green small type of aubergine to the passing potential customers. Camille fortunately gave me an umbrella to protect myself from the blazing heat, while she sat next to me on a small wooden bench – to my incomprehension, in her red woollen hat. With her one hand strewn with burn scars, she piled big and small heaps of tomatoes and onions on a tarpaulin in front of her with swift, skilful movements. When she made a deal with a customer, she took one of her small transparent plastic bags, rubbed it on the cloth wrapped around her waist, opened it using her lips and blew it fully open before she gave it to the buyer to hold while she filled it with the tomatoes or onions.

For heavy physical work, like carrying a basin full of tomatoes, she usually received help from the neighbouring market women. They seemed to be used to helping one another, looking after each other's business during temporary absences or changing money, as I observed. Between exchanges with her clients, Camille discussed amounts and prices of the produce with her neighbours. In contrast to the impression she had previously given me as being rather taciturn, she was forthright in instructing me how to help her with customers, piling up tomatoes and the like. She taught me the practice of *kuongeza*[2] – to top up a purchase with one or two of the small or cracked tomatoes from the basin next to me, or with even more, when the customers were her acquaintances or friends.

Camille had already pursued market business in Congo, between Goma and its surrounding villages. When she was carrying goods on a bicycle on the way to Goma one evening in 1997, an armed group had attacked her and other traders during their night break. It was then that she had lost her right arm:

> I was in a group which was caught and put inside a house, which they locked before they set it on fire. There was a strong man who broke the wall and, as he was escaping, I caught hold of his trousers and got out as others were burning. We ran into the forest but, because I was weak, the man left me and later informed my people that I had died in the forest. People came to the forest to look for my body and that is when they found me crawling. They took me to the hospital as my arm was severely burnt.

In the hospital they had to amputate her arm at her right shoulder, while other parts of her body, including her face, were badly scarred by burns. Almost ten years later, in 2008, a battle between the Congolese army and the CNDP (National Congress for the Defence of the People) rebels broke out in Goma. This forced Camille, her husband and son to flee to a border town, until that town was also attacked, which led them to cross the border into Uganda.

Most of the times when I met Camille she went about her business and other daily activities in the absence of family members, as her husband lived and worked as a football coach in a boarding school in a Ugandan town about three hours away by public transport. Her teenage son had moved to the nearby lake to make his own money by fishing, after he could no longer carry on at school

---

[2] *Kuongeza* is the Swahili word for 'to add'.

for financial reasons. Camille often explained how hard life was in Kyangwali compared to Congo. She thought it was particularly problematic that survival in Kyangwali was based on agriculture: "You see, I did not know how to dig [farm], but when I came to the camp, I learnt how to dig. In the camp, if you don't dig, you can't get clothes, you can't get soap. The life here is hard for me. It has exceeded my capacity". Whenever possible, she and her husband hired people to cultivate their fields, but they often lacked sufficient money, and several times I came across her sweating as she had just returned from weeding the fields. Luckily, she had a close friend from Congo in a nearby village, whose children she asked to assist her with tasks such as transporting food rations.

The first time I visited Camille at her home, she had just moved to a new place in the centre of a village directly beside the road. Topped with a tarpaulin, the hut was crooked and its walls cracked in several spots. Camille rented this place for 5,000 Ugandan shillings[3] per month, an amount that she was not always able to pay on her own. She sometimes had to ask her husband to send her the amount via mobile money transfer. Contrary to her expectations, she was not eligible for housing support from the aid agencies, because she was assumed to be living with an able-bodied husband. Despite the rent and the house's condition, Camille was glad to be in a safer environment than in her previous home far away from the village centre, where someone had broken into her hut and stolen her savings. Camille expressed her unease with other people in the village: "These people here have a lot of jealousy. They follow every step I take. Whether I go out of my house or enter it, their eyes follow". A friend who had visited from Congo had helped her restart her business after her money was stolen. But she said that she did not have many friends in Kyangwali.

I visited Camille another time at home after I learnt that she was vice chairman of the settlement's disability association that had been initiated by Aid Global. I was interested to find out how many people with disabilities lived in the association's zone that she represented. From the second room of her hut she brought one of those common grey schoolbooks with a paperback cover to show me a list of people with disabilities. Before she gave it to me, she put the book on a sack of maize to add another name with some information in her neat handwriting. After she had lost her arm, she had learnt to write with her left hand, and she laughed shyly when Amani and I praised her writing skills. She once told me that a person could learn anything.

---

[3] Approximately 1.4 US dollars.

During the course of my interactions with her, Camille described her experiences with her disability in manifold ways. Referring to her neighbours, she said: “They underestimate me, others abuse me. Some say, ‘Why does her husband love the cripple? How will staying together with that cripple help him?’ It hurts me”. She then continued: “I was better before. With this disability, many things have changed. I used to do all the work myself but now I have to beg people to help me. And if they don’t, then that work remains undone”. This was the case, for example, with washing clothes. Camille accumulated her dirty clothes until her husband visited from Hoima to wash them. This sometimes left her only with dirty clothes to wear for days.

During another visit to Camille’s, I finally met her husband Yannik, as it was the school holiday. He stood on a ladder under a newly-built reed extension to the hut, while children handed him the clay with which he plastered the reeds. We chatted for a while, as Camille had not yet returned from church. Yannik told me that he was not feeling well physically, since he had injured his arm playing football and, although the aid agencies had been informed about this, they still expected him to do the construction work himself. This had only resulted in more pain in his arm. Just like Camille, he stressed that he would like to return to Congo where they both had relatives, especially in and around Goma. Soon Camille returned from a service at a new Pentecostal church, which she had recently joined and was attending every Friday and Sunday. She was looking smart in her long *kitenge* dress.

∴

Anthropologists have shown that care not only encompasses social belonging and emotional attachments (e.g. Drotbohm and Alber 2015), but is also interwoven with emergency situations that legitimize specific forms of humanitarian intervention (McKearney and Amrith 2023). States, together with non-profit organizations, make decisions about which populations in other parts of the world need or deserve humanitarian assistance, and which groups within them are considered to be in particular need of help – depending on their perceived vulnerability, but also on notions of “unjustified and innocent suffering” (see Ticktin 2011a), which seems to be especially relevant for children or people with disabilities (see also Dahl 2014; Malkki 2015). Vitali and Camille’s stories indicate diverse dimensions of dependence, independence and interdependence in regard to daily activities and practices of care. They managed many of their everyday tasks on their own, while they depended on the support of friends, family and neighbours for others. The aid organizations were oddly absent from their stories. This chapter starts from this obvious disconnect between humanitarian assistance and how people managed their lives on a daily basis. This disconnect calls into question the very rationale of humanitarian aid for 'vulnerable' people.

In Kyangwali, aid workers and refugees alike used the Swahili term *watu wasiojiweza* for 'vulnerable' people. The term literally meant 'people who are not able' but was mostly translated or explained as 'people who cannot help themselves'.[4] The alleged inability and dependence of a 'vulnerable' person involved activities like farming, fetching water, building a house or collecting firewood. The actual support of the aid agencies for 'people who cannot help themselves' was, however, greatly limited in this regard: it was basically about provision, and did not assist people in activities such as transporting food rations, nursing, cooking, going to the shops, getting to hospital or washing dishes. Instead, the aid agencies promoted what they called 'community support' for several reasons, yet mainly with the aim of avoiding dependency on their aid.

In many places in Sub-Saharan Africa, it is the role of specific members of an extended family to take care of sick, disabled or elderly people, as well as orphans (McKearney and Amrith 2023). Caregiving is often seen as a moral social obligation, with women expected to provide the majority of care (Manderson and Block 2016, 211). For disabled people in Kyangwali, their changed circumstances meant that they now lacked certain social relations. In this chapter I will therefore examine what kinds of care relations were formed and used in a context where a kinship network was largely absent, and consider what difference the aid system made in relation to this situation.

First, I will consider how the aid agencies understood and approached 'the community', and how disabled people lived together with other refugees in Kyangwali. I argue that it was challenging to generate the aid agencies' desired ideal of community support because people had to manage their lives without their extended family and because moral obligations were less binding in the diverse, unrelated society of a refugee settlement. It is interesting to note that some of my interlocutors thus expected the aid agencies to assume care responsibilities analogous to those of family members (see also Ferguson 2015: 49).

Second, I will look at how, alongside this pervasive focus on community support, the ideal of an individual, independent self was also being promoted. As an example of this, I will focus on Aid Global's project 'Inclusive WASH', as it promoted this ideal in regard to people's daily activities around water,

---

[4] The Kinyabwisha term *batishobwoye* was said to have the same meaning.

sanitation and hygiene. I will show that disabled people in Kyangwali did not want to be independent in all regards, sometimes preferring to even seek dependent connections with others. I argue that Aid Global's approach did not recognize or value the manifold ways that disabled people were supported by their social networks, so promoting this ideal of independence undermined the reality and importance of connectedness.

What became apparent through the case studies was that people with disabilities were always both receivers and providers of different forms of care that went beyond what the service providers thought comprised people's needs and abilities. I take care as meaning not only practical or bodily care, but also involving other activities that contribute to a person's general well-being. This includes gifts of money, visits or, for example, attendance at funerals – any actions with which people expressed their concern (see also Livingston 2005, 197). With this approach, I thirdly aim to provide a differentiated view of "people who cannot help themselves" by describing how disabled people practiced and received this care.

The way in which care relations found expression in Camille and Vitali's stories showed that they were not institutionalized through the service providers. This also raises the question: how could a person with a disability in this setting mobilize people to help them? In a fourth section, I will thus look at reconfigurations of care, to scrutinize how displacement and the provision of aid brought about practices of caregiving among neighbours and family. I argue that, instead of simply fostering aid dependency, access to aid and special opportunities actually enabled care relations, as it repositioned disabled people to become useful connections for others.

3 The Desired Ideal of Community Support

Vitali and Camille made use of a diverse, although rather different, network of people with whom they practiced care relations. Vitali's network included a large number of neighbours and members of the Muslim community, and he fostered strong ties with his nephews in Kampala. Camille was well connected with church members and her fellow market traders, and a few friends who she knew from Congo. In contrast to Vitali, who had an openness towards others that made it easy to make friends, Camille was rather disturbed by living among people she did not know, who she felt had a hostile attitude towards her.

Most disabled people I interacted with in Kyangwali lived with a spouse and children, and only a few had no close family members nearby, like Vitali. As was the case for Camille, close family members sometimes lived, studied, or worked at least temporarily outside the refugee settlement, sometimes as far as in Kampala or even somewhere in Europe or the US. Some of my interlocutors might have a sister, an uncle, a few cousins, nephews or nieces around, but it was the absence of a broad kinship network which made the crucial difference between how people lived together in a refugee settlement compared to other places. Disabled people often expressed the difficulties they encountered through this. They recounted that in Congo, for instance, they had received support from relatives in situations where they lacked food, money for school, or when a child fell sick and they needed to buy medicine or pay hospital bills. It was due to this absence of an extended family network that disabled people thought it was the aid agencies' responsibility to care for them. A disabled woman explained: "You come to find that life here and in Congo is very different, so much. Because here you stay only with your husband and the children. Here in Uganda I don't have brothers or sisters, so if you get a big problem like the one I got [her hut burnt down], for sure those in the offices are supposed to help me".

However, the aid agencies saw it as the 'the community's' responsibility to care for 'vulnerable' people. In a community-based approach: "[r]efugees must be encouraged to help themselves by using their own skills and resources from the beginning of an emergency" (UNHCR 2007, 8). In capitalist economies, care work and dependency are typically associated with the private sphere (McKearney and Amrith 2023). Peregrine Horden and Richard Smith point out how, in the second half of the 20th century, many states closed long-term care facilities and shifted to the idea that care can best be provided in the 'community' (1997). At the same time, in today's European welfare states, especially the Scandinavian ones, relatives are less and less expected to provide care without state compensation, while the state offers extensive alternatives to have people cared for professionally by non-relatives (Altermark 2018). This tendency, however, was not at all the case in Kyangwali.

An aid worker explained their strategy of trying to foster community support to avoid generating dependency: "It's most important that we keep the people concerned in this community structure, so that we do not create the impression that we have to give them everything. That we are maybe going to get an outside caretaker to come or, for example, a maid. We don't do that". He continued by explaining that the UNHCR tried, as far as possible, to strengthen this aspect of community support, but he was conscious about the different expectations many people with disabilities had: "Of course, there is also a feeling that, because I am disabled, because I am an EVI and was verified by the OPM or the UNHCR – they think this is a person of the UNHCR. But we are trying as much as possible to sensitize these people to go back to the cultural values within the community". This neoliberal logic, in which institutions shift responsibility to the community by actively encouraging them to care for their fellow human beings, seems to be more strongly demanded or expected in the global South than in the global North. There seems to be a certain idealization at work: that such community or family-based care practices are somehow naturally occurring within some cultures and that these values must be upheld (see also Thelen 2015, 500).

The UNHCR's community-based approach aimed to rebuild an intact community that was held together by "normal and traditional community structures", which they perceived as having been broken down through displacement (UNHCR 2007, 182). It did not, however, further explain exactly who this community was or should be. While the aid workers spoke about a sort of self-explanatory 'community', such an entity did not seem to be evident in the eyes of many refugees depending on other people's support.[5] Thus, conceptualizing a 'community' as an already given entity could be seen as a strategic simplification of homogenizing and binding a politically and socially diverse field in motion, in order to be "mapped, organized, mobilized, and intervened“ (McKay 2012, 56). This facilitated applying the UNHCR's community-based approach, which predominantly engaged with the community via two important institutions: community social workers and community leaders.

Community social workers were central figures in the principle of community-based support. When talking about how a disabled person without a family member could access the food distribution, an aid worker explained: "It is the role of the community social worker to make sure that, during a food distribution, the EVIs can collect and transport their food. It is also the responsibility of the social worker to make sure that an EVI gets water and firewood". As described in Chapter 3, community social workers found themselves in the ambivalent position of being representatives of both 'vulnerable' people and the service providers. This position raised the question of who their loyalty lay with, especially since two suitable candidates for this post were chosen through votes from community members, but only one was eventually appointed and paid a small allowance by the aid agencies. Rafael (case 2), for instance, had been tricked by his community social worker, who was supposed to collect his food rations, but did not deliver them for months.

---

5 Vitali and Camille, as well as other people with disabilities, did not talk about 'community members' when they referred to significant others, but used more specific descriptions like 'friend', 'neighbour', 'woman in the market', 'fellow disabled person', or 'people from the church' (see also Whyte et al. 2014).

Other care arrangements that were initiated by the aid agencies did not work out as intended. This was the case for Vitali, who was a beneficiary of an agricultural assistance programme. Due to his inability to pursue farming, Vitali was targeted as one of seven people categorized as EVIs to be supported by an annual assistance programme from Africa Help Mission (AHM). The organization paid someone else to cultivate Vitali's plot of land. However, he told me that he did not get much out of the scheme, as the man working on his field only did half the job. All four of the disabled people I met who were supported by this agricultural assistance programme during my fieldwork period, including Rafael (case 2), made similar complaints that the people hired had not completed their work properly.

The aid agencies' guiding principle in regard to 'vulnerable' people was that solutions that were not community-based should only be a last, short-term resort, until functioning community support mechanisms could be identified. This happened to one disabled person I knew. Martin (case 9) had a number of women cooking for him, washing and helping with his personal hygiene. One of the aid workers explained that it was difficult to find carers for disabled people once they learnt that they would not gain any extra benefits, like certain material goods or financial support. In regard to Martin he told me: "We have been trying to get someone to prepare food for him and also to escort him to the latrine. That [paying someone] is the approach we had to take. As much as that is not what we usually do, for extreme cases we are sometimes forced to do it". Martin's case was exceptional because of how much the organizations were involved in engaging with his care relations.

The way people lived together in Kyangwali was, to some extent, different from what was often perceived as 'local communities' in other contexts.[6] When aid organizations recruited people to do voluntary work for implementing health projects or development aid in other settings, those people were usually linked to the population in their village or region through kin connections (see e.g. Livingston 2005, 227; Swidler 2009, 203). Familial and communal ties certainly existed in Kyangwali, but they were fewer. The position of social workers and other hired individuals was more imposed upon a community

---

[6] The OPM allocated land to refugees by zone, so when one zone was full it moved on to the next one (DRC 2018, 2). As Congolese refugees fled at varying times, due to different centres of the conflicts, they more or less stayed together in their ethnic constituencies in Kyangwali. The OPM tried to promote peaceful co-existence between the different ethnic groups in the settlement. However, the newly-settled refugees tended to search for their ethnic, cultural and linguistic community and thus informally relocated if they were placed in different areas.

with such a disparate society as in Kyangwali, and the moral implications of serving in those positions could be less binding.

The second way that aid agencies engaged with ‘the community’ was through community leaders, such as village chairmen and other representatives of local councils. In the case of ‘vulnerable’ people, special attention was paid to church leaders to mobilize ‘the community’. One of the aid workers explained:

> We work together with churches. We provide them with drums and other items for the church community, so we can rely on them when it comes to gaining their support. If we don’t have money to construct huts, we ask the members of the church to build for the people in need. If the person in need prays at that church, then this is often possible.

Livingston writes about how independent churches in towns provide an important social anchoring point for people who migrate there for work. The relationships built in these places were found to be supportive when people were ill or had problems with money or finding employment (2005, 251). Different church congregations seemed to pop up like mushrooms in Kyangwali.[7] Aid organizations attributed such importance to faith-based institutions that they encouraged disabled people to join a congregation, if they were not yet part of one. An aid worker furthermore explained: “We are trying to encourage not only church members, but also young people to try and offer support, for example in fetching water, [collecting] firewood and whatever kind of assistance a vulnerable person may need”. This seemed like quite an idealistic standpoint, expecting that young people would be eager to voluntarily help others, especially when their own situation was in all likelihood somewhat critical as well, and the resources they had to support others were very limited (see also Bakewell 2003, 13; UNHCR 2003, 65–66).

The desired ideal of community support and its rationale of avoiding aid dependency were challenging, because disabled people had to manage their lives without extended families and because moral obligations to support certain members of the community were less binding in that context. Furthermore, it was unrealistic to expect people to help others when they were already struggling to get by themselves. Vitali and Camille’s stories, however, show that many such communal support structures certainly were in place in the settlement. Despite the emphasis the aid organizations placed on community-based

---

[7] Gaining permission to establish churches in Kyangwali was less restricted and formally less controlled and monitored than was the case for aid institutions.

support, it seemed that they did not value existing care relations much. This will be discussed in the next section, which examines Aid Global's approach of promoting disabled people as independent actors in regard to how they carried out daily activities around water, sanitation and hygiene.

4 The Contested Ideal of an Independent Self

Aid Global's 'Inclusive WASH' project aimed to increase access to water, and to improve sanitation and hygiene for disabled people. A report compiled at the end of the project described one of its outcomes as disabled people's "reduced dependence on other people for WASH needs".[8] During their project, Aid Global drilled 16 new boreholes. With a ramp, a concrete block to sit on, and a handle at a height where everyone could reach it, their design promised access for wheelchair users as well as for people who were not able to stand. The disabled people I interacted with in Kyangwali generally appreciated the new boreholes, even though they did not use them as intended. When I asked Claire (case 7), a disabled woman, about Aid Global's project, she said: "Yes it helped, it helped very much. We did not have a lot of water here, we only had one borehole, and you would find that the children suffered every day. But Aid Global put a lot of water here. Today, children fetch [water] wherever they wish".

As in other African contexts, it was very common for children in Kyangwali to be responsible for fetching water (see e.g. Dahl 2014, 638; Livingston 2005, 215). Disabled people without offspring often relied on neighbouring children for this task. Vitali usually rode with his jerry can on his tricycle to the borehole, where he always found someone to pump water for him – boreholes seemed to be popular meeting points for children and teenagers, especially before and after school hours. For those disabled people who would have preferred to fetch water independently, it was often getting to the water pump that proved a challenge. Even though the new water pumps had ramps, their environs were often wet and slippery, thus difficult to manoeuvre with a tricycle or on crutches.

Another technology which promoted the ideal that disabled people could do as much as possible on their own was the 'jerry can tipper', an iron scaffold designed to reduce the strength needed to handle a jerry can, as it meant that a user only needed to tilt the device in order to pour water, instead of lifting the jerry can itself. Aid Global distributed these water storage devices

---

[8] Aid Global, project brochure, 2015.

to 70 households, but in many cases I found them lying idle amongst other belongings or set aside behind people's huts. For instance, Daniel, who was bedridden, asked his daughter to bring a cup and basin to his bed and pour the water over his hands after he had finished eating, while the jerry can tipper stood unused in the corner of the room.

Vitali was the only person I ever saw using this device. Placed next to his mattress, he tipped water into a drinking cup, or washed his hands before eating. Yet, if Vitali needed to wash clothes, he also received help from neighbours who brought water into his compound and helped pour it into his basins. Vitali's everyday routines and the help he received reflected an important factor that the project's water storage device did not take into consideration: in the settlement, there were different places where people ate, washed dishes or clothes, bathed and cooked. The range of locations where water was needed daily meant that this technology had to be mobile. Perhaps because of its unwieldy design, it turned out to be easier for disabled people, as well as for the people that supported them, to simply carry a jerry can to these different places, rather than to move the whole iron scaffold.

The efforts made and strategies applied showed how much Aid Global's intervention was fostered towards the ideal of an independent self which was, in the above-mentioned ways, contested. Nevertheless, being more independent was certainly what people with disabilities also wished for. When Camille talked about what she could or could not do, she did so in individual terms. She explained how much the disability had affected her ability to manage daily tasks. In contrast, Vitali described how interactions with other people had enhanced or restricted his capabilities. Camille seemed to treasure independence as a state of being able to carry out practical tasks within her household or business without relying on support from others. Vitali instead expressed his sense of independence in terms of work, having an income, and being able to purchase the things he needed. He had experienced dependency on other people in daily tasks since childhood. Dependencies were thus experienced in very different ways, while the disability itself, its onset, a person's social networks, along with customary gender roles and age all crucially shaped those experiences.

The pit latrines that Aid Global provided for 280 households in Kyangwali were certainly very important for disabled people. In order to make it easier for people with disabilities to use the toilet, additional devices in the form of a wooden seat with a hole in aimed to ease disabled people's use of latrines and alleviate the difficulty of squatting. Many disabled people appreciated the new toilets, and some said that the additional devices eased their visits to the toilet considerably. Claire explained: "They brought that seat and now it is like I am seated here [pointing to the bench she sat on], my back does not hurt any more”. Some of my interlocutors, however, were not able to use the toilets at all. This was the case for Rafael (case 2), for example, who had to be lifted to the toilet by his neighbour Mohammed. As Mohammed was not always there, Rafael also used the cut-off bottom of a jerry can to relieve himself inside the hut, to be cleaned out afterwards.

A promotional video that Aid Global released at the end of their project featured Vitali in it, showing how he moved off his tricycle and crawled into a toilet hut with a wooden seat, accompanied by swelling, hopeful music.[9] This surprised me, as Vitali had told me members of the Muslim community had constructed a latrine for him as an annex to his hut, explaining that “the outside latrine was not convenient for me”. The video also followed Vitali as he pumped water and showed him and other disabled people happily washing clothes. Even though Vitali sometimes liked to wash his clothes by himself, his neighbours helped him to fill the washing basins and hang the clothes up on washing lines. Whereas the promotion of the ideal of disabled people who can manage daily tasks independently was in some ways echoed by my interlocutors in Kyangwali, the way disabled people were represented in the video seemed to undermine the importance of the care that was provided for them.

Apart from the voices of disabled people expressing their gratitude to Aid Global, there was no place in the promotional video for Mohammed’s efforts lifting Rafael into bed, a neighbour fetching water, or Vitali’s Muslim friends constructing a useful toilet for him (see also Livingston 2005, 202). The promotion of an independent ideal of personhood in Aid Global’s approach undermined the often necessary and desired relations of dependence that disabled people engaged in. It masked the extent to which many people with disabilities had to rely on others for daily tasks, but it also ignored the importance of connectedness for disabled people – not only in receiving care, but also in terms of their personhood. The next section examines care as something that is inherently interdependent, and takes into account the daily activities that went beyond people’s basic ability to function.

5 The Importance of Connectedness: “Checking on Someone”

The way aid agencies in Kyangwali perceived people’s vulnerability was closely linked to classical and instrumental activities of daily living, which

---

[9] Aid Global, promotional video, 2015.

looked more or less closely at self-care, domestic life, household chores and movement.[10] Care relations, however, go beyond what enables a person's fundamental 'functioning' in these terms. Being cared for and being helped out in critical situations is closely intertwined with activities like visiting others or attending social gatherings. Such social events were crucial for creating and nurturing social relations that often went beyond kin, and thus were even more relevant for people in Kyangwali. Moreover, such activities were not just important opportunities for nurturing relationships, many of them were also simply enjoyable.

Vitali frequently had visitors at his home when I dropped in, and sometimes I encountered his tin door closed and neighbours informed me that he was elsewhere, "checking on someone". That phrase meant expressing concern for a person's well-being. Several times when I returned to Kyangwali after staying in Kampala for a while, some of my interlocutors questioned why I had not "checked on them", even by phone, in my absence. Vitali's friend Alex often 'checked on him' in the evenings before his night shift as a guard for one of the aid agencies, and brought him some cooked food or the popular street food *rolex*, an egg omelette rolled in a *chapati*.[11] Vitali in turn visited Alex and his mother at the place where they reared their poultry.

Some people liked to go to a neighbourhood bar or to spend their leisure time with others in different ways. Odongo, one of my interlocutors from South Sudan, rode his tricycle nearly every day to the centre of Kyangwali to play cards with his friends from South Sudan in front of one of their shops. Others were found reading the Quran together or simply sitting at a neighbour's place chatting. When visitors came from farther away, like Kampala or Congo, possibly for a relative's funeral, they often brought presents or dropped by to give a contribution, as, for instance, Camille's friend had done, giving her the means to help her restart her business after her money had been stolen.

Going to church, visiting friends or attending someone who was ill demanded mobility, which is why disabled people's possibility to take part in such activities and, thus, their "ability to return care with care" was often

---

[10] Classical activities of daily living (ADL) include self-care such as personal hygiene, dressing, toilet hygiene or feeding yourself. Instrumental activities of daily living (IADL) entail what enables a person to independently live in a community, in regard to domestic life, household chores, and movement. Service providers mainly in Europe or the US tend to refer to this standard repertoire in order to evaluate people's eligibility for all kinds of assistance (see e.g. Heller and Harris 2011).

[11] A *chapati* is an Indian flatbread that is found throughout East Africa.

limited (Livingston 2005, 19). Mansanga (case 1), for instance, felt bad that she was not always able to fulfil what she imagined to be the role of a good grandmother. When her adult son was not around one day, and the school expected a child’s guardian to be present, she was unfortunately not able to travel to the school without a tricycle. My other interlocutors who were not lucky enough to receive a tricycle regretted being unable to get to church. Attending church or any other faith-based institution was not only done for religious purposes, because those institutions also served as a meeting point, a place for news announcements, and recreational activities with music, singing and dancing. Furthermore, they could also be a crucial initiation point for receiving care, as described above.

Relationships with church members were also crucial when someone was admitted to hospital, for example. It is very important within most Sub-Saharan health structures that a person is accompanied when they are admitted to hospital. In most hospitals, patients are only attended to medically, so it is the responsibility of family and friends to provide nursing care, including cooking for and feeding the patient, bathing them and washing the bed sheets they would have to take in with them. When a disabled woman I knew was admitted to hospital, it was members of her congregation who visited on a daily basis to pray with her, take her food and assist her in other ways.

Disabled people’s diverse relationships were not only vital for receiving care in these manifold ways, but they were also an important feature of their personhood, especially as they were also providing, sharing and contributing to these relations. Giving advice can also be understood as a form of care in this sense. Alex explained how he had tried to convince Vitali to stop drinking and smoking, for example, because these habits were damaging his health – especially at his age – and he often suggested that he should drink juice and eat healthy food. On the other hand, Alex appreciated the advice Vitali gave him in other areas of life. He explained that, as a young man, he enjoyed the older man’s company, especially as he had so many stories to tell about other countries. He stated that he particularly appreciated Vitali’s advice on budgeting and spending money. For instance, it had been Vitali’s idea to start their chicken and duck project.

Visiting someone and helping out with financial matters, giving and receiving advice, and attending to ill people were all ways to create care relationships. What was specific to refugees was the role that kin and non-kin relationships took on through displacement and in the context of aid provision. Both ‘the community’ and resources acquired as aid seemed to have become relevant factors in shaping care relationships. The next section discusses such reconfigurations of care among disabled people in Kyangwali.

6 Reconfigurations of Care

Anthropologists have described not only how disability can lead to reconfigurations of care relations within families (see e.g. Rapp and Ginsburg 2001), but also how aid or broader political and economic developments can lead more widely to reconfigurations of care (Dahl 2014; Livingston 2005; Manderson and Block 2016). People with disabilities in Kyangwali had not only experienced drastic changes in their social networks, but some of them had also acquired their disabilities during war or flight from conflict. As they and their families were furthermore eligible for support from the aid system, all of these circumstances played a role in how care was provided and received.

All those who had fled Eastern Congo or had already lost relatives during the long duration of the conflict there only had a reduced network of extended kin left. Yet, this became especially visible and critical for people who found it more difficult ‘to help themselves’ than others. Livingston describes how, in Botswana, when young women increasingly migrated to take part in the town’s wage economies, they could rely on other female family members to take over nursing care of dependent kin (2005, 214). Most people in Kyangwali were no longer able to draw on such extended family networks, and the children with disabilities I met in Kyangwali were in particular need of permanent care.

Nova was a three-year old girl who received dedicated care not only from her mother, Angelique, but also her husband and one of the two other older children. Angelique constantly needed to wash clothes, especially in the rainy season, as Nova crawled everywhere with other children her age who walked, but also because she continually urinated and defecated on her clothes. This was not just a lot of work, but also a financial burden to keep buying soap so often. As her mother needed to carry her everywhere, she also struggled to earn an income and was not able to work in the fields: “I cannot stay away from her. In whatever I do, she has to be nearby and that is a problem”. Angelique explained how the situation would have been very different in Congo: “We had many relatives like my older sister, my younger sister, uncles and their wives among others, and all of those would sometimes come and help”.

I often observed in Uganda that younger women lived in a relative’s home for a while to take care of relatives’ newborn babies and household chores. These tasks were considered to be those girls’ responsibilities, or even part of their social education. The absence of such a care network had not been considered by the aid organizations in Angelique's case. After living in Kyangwali for a while, her family's food rations were reduced to 50 percent of the initial amount. I frequently visited them in the small restaurant that Angelique rented in the centre. She told me that it was easier to sell hot milky tea and fry cassava while simultaneously looking after Nova than trying to work in the fields with her.

On the one hand, aid workers were concerned that the level of support disabled people received within the community would decrease if the service providers delivered too much assistance. On the other hand, they also worried that disabled people's potential aid might be taken advantage of by people who were not relatives. An aid worker explained:

> Maybe a person wants to help, but we are trying to prevent this person doing it for his or her own benefit. Sometimes when they take care of someone, they start going to all the organizations, seeking sympathy from everyone: "See, I am looking after this disabled person, I need soap, this and that, other materials". So we make it clear that they cannot do this for their own benefit and start asking for help.

Since there were usually no incentives for people to take care of disabled people, why was it that, in so many cases, people took care of disabled people with whom they had no kin ties?

When I asked Mama Goretti, who took care of Vitali, she said: "I just saw him having needs, so I said I cannot leave him alone". The motivation people stressed most can best be grasped with what refugees in general referred to as 'Samaritans' or 'Good Samaritans' taking care of elderly and disabled people. This expression is a reference to the biblical parable of the 'Good Samaritan', about a traveller lying in the road after being robbed, stripped of his clothes and beaten up. As it was a Samaritan who helped this traveller, the expression 'Good Samaritan' serves as a metaphor for someone who kind-heartedly helps a stranger in need. The thought of being rewarded by God for altruism seemed to play a role for many people as, for instance, one carer expressed: "What I am doing for him [a disabled man], God will reward me for, but I do not help him to get something".

Some carers also referred to the bond of speaking the same language or being of same origin. Kabunji, an old man who could only move very slowly with the help of two crutches due to painful back and hip problems, was cared for by Gloria's family. When Gloria's family had arrived in Kyangwali, they had built a hut for Kabunji in their extensive compound so that he could move out of the hut with a plastic sheet he had been living in beforehand. The family cooked food for him, fetched water, washed clothes, and helped him out with whatever he needed, including buying clothes, matchboxes, bathing soap or cigarettes, as Kabunji told me. He said: "Those people [Gloria's family] met me here in the camp, and we speak the same language. So being of the same language, they said I could put them [on his resettlement document]. When I got a form to go abroad, I put them on my letter, so we were like one family". There seemed to be something else at stake besides speaking the same language.

I have already noted the important role that food aid played in enabling disabled people to forge care relationships. The option of resettlement seemed to be a similar kind of assistance that other people sought access to. At the time of my research, resettlement was only a possibility for people who had arrived in Uganda before 2009. People among this group who were without family but in need of care had the chance to be resettled together with their carers. Although Gloria's family had only arrived in 2011, there were ongoing discussions about them being resettled together, as Kabunji was eligible for resettlement, having already arrived in Kyangwali in 1997.

I was often unable to obtain clear information in cases of non-kin relations and resettlement status, and all the carers I spoke to emphasized that their motivation was purely altruistic. This suggests that altruism and strategies for personal benefit are not mutually exclusive, but often go hand in hand. Anthropologists have shown how different types of relationships are formed precisely because of the intersection of affection and money (e.g. Constable 2009; Gutierrez Garza and Paola 2019; Zelizer 2009). Scherz talks about the overlapping of self-interest and altruism within relations of patronage as a moral obligation in Uganda, where "one stands to gain some combination of material, symbolic, or spiritual capital by taking on dependents, while such an action is simultaneously thought to be an act of altruism, which is at times obligatory" (2014, 19). Such relationships never mean solely altruism or generosity, nor simply selfish advantage seeking, but are moral relationships of obligation and caring as well as interested exchange (Ferguson 2015, 133–134).

I observed how aid shaped care relations in other situations. When I discovered that Vitali's nephews Lionel and Youssef had moved away to work in Kampala without leaving any other family members behind to look after Vitali, I wondered whether their move had been enabled by the fact that Vitali received aid. I met Lionel in a busy takeaway restaurant in downtown Kampala, where he told me more about that time, surrounded by loud voices, booming bass music, and the nearby traffic noise:

> Let me tell you this, my coming here to Kampala was not easy. Because there was even a certain time when Vitali thought we had dumped him. Sending money was not enough, it was little. So it was maybe not satisfactory to him. He put his anger towards us, that we should not dump him. We countered him, saying, "*Mzee* [Swahili for old man], we are helping you, we have not forgotten you". But it was not enough. Because he needed constant care, someone to wash for him, so money was not enough.

Livingston asserts that social security payment schemes like old age pensions have rendered the younger generation less readily willing to take full responsibility for their older kin in Botswana (2005, 208). Bianca Dahl observes how assistance to orphans in a Botswana village challenged local caregiving practices in a somewhat different way. When government food aid was distributed to households during the AIDS crisis, the elderly within the community in particular feared that the moral obligation to take care of the family's orphans would wane with this assistance (2014, 633).

I do not know whether the aid Vitali received reduced the level of responsibility that his nephews felt towards him. I would argue, however, that the aid Vitali received enabled caring relations with non-relatives to occur. The food aid Vitali received certainly allowed Mama Goretti to take care of him, whereas Lionel told me that, without someone like Mama Goretti, he and his brother would not have been able to leave their uncle behind. Furthermore, although aid might have reduced the need for their physical presence to nurse their uncle, they were nevertheless an important source of care since, at various times, their income supported Vitali financially when he needed money for medicine, soap or *airtime*. It was, for example, Lionel who had bought Vitali a phone.

In the absence of extended social networks new care relationships emerged, which combined kin and non-kin relations. As Mama Goretti commented: "When they [Lionel and Youssef] reach here, if I am taking food for Vitali and one of them is around, I also take food for them, because they are also part of the family". Mama Goretti called Vitali her father and the grandfather of her children. She explained: "I do not know his family, but I see him as my father. Even the children and many people think he is my father. And when they ask me I agree and say yes, because they know how long we have been with him". Anthropological literature demonstrates that it is common practice among refugees for relationships with friends and neighbours to be transformed through care and everyday activities, and expressed and experienced in familial terms (e.g. Clemens 2008, 35–36). The point that kinship is often not only defined by birth, but can also be created through repeated acts of caring, is not unique to displacement settings (e.g. Carsten 2000, Durham 1995).[12] Yet, it seems to be more essential to create and nurture such relationships when extended families are absent.

Lionel told me: "In Kyangwali, we do not have any other relative apart from, you know, friends. When you stay over with a person, she or he becomes your relative, so you can go a long way [together]". Amani expressed it perfectly, saying that such relationships could be understood as being experienced as close and caring, when he translated and elaborated more on what Mama Goretti and her husband had to say about Vitali's son, who had recently appeared in the refugee settlement: "They do not think that he is his son, because they see that the boy does not even take care of him, and does not even visit, that's what they think. So it means, maybe he is not his son". Vitali referred to this teenage boy as his son, but did not often talk about him. He thought that his son was struggling on his own, when he was busy trying to earn some money by making *chapatis* or as a *boda boda* driver.

7 Conclusion

This chapter has challenged the assumed inability and dependence of disabled people as inscribed in the humanitarian assistance categories, by describing their daily activities and practices of care as being inherently interdependent. Disabled people experienced physical inability, dependence or independence in very diverse ways. Yet, in contrast to the dominant Western understanding of an individual form of personhood, people in Kyangwali were not necessarily looking to achieve independence above all. Instead, they wanted to be related to other people in certain ways.

Thus, the individualistic model of disability that Aid Global implemented through its project did not fit well into the social fabric of the settlement, where social ties turned out to be very critical for enabling disabled people to access and use water, as well as in regard to other daily activities. Aid Global's iron scaffolding and inclusively-designed boreholes that merely aimed to enable an independent disabled actor undermined the role that relations of

---

[12] However, there is also an important critique to be made of this view, namely that similar care practices in a European context would likely be classified differently by researchers, for example as friendship (see Thelen 2015, 501).

dependence play in the emergence of personhood. Similarly, the assumption inherent to the humanitarian assistance categories that people with disabilities were care-dependent ignored the many ways that they were also care providers, and how they contributed to their social networks.

Furthermore, the chapter has challenged dichotomies of dependence and independence, by demonstrating that the ideal of community participation was closely connected with the aim of preventing aid dependency, whilst realizing that this aim actually required disabled people to be heavily dependent on their social networks. Reliance on 'the community' appeared to be an especially critical endeavour in a refugee settlement where people were not linked by time or familial ties. In such a context, relations of patronage, enabled through aid, had become particularly important for many of my interlocutors whose extended family networks were largely absent. The chapter has demonstrated that access to aid and opportunities such as resettlement actually fostered and strengthened care relationships, rather than weakening them.

Thus, the cases of non-kin care relations depicted in this chapter do not necessarily support the common narrative within humanitarian discourse, that "the loss of family members or caregivers during displacement leaves older refugees with disabilities more vulnerable and isolated than they were back home", as stated in an online article by the organization 'Help Age' (Mazunda 2017). Losing family members and caregivers could certainly render disabled people more vulnerable, but the special aid and recognition they received in the refugee settlement also repositioned them, enabling them to become promising connections themselves. Rather than being isolated, Vitali, Rafael, Kabunji and Martin – all of them elderly – were looked after and taken an interest in. The need for more stability through access to increased aid, and the hope of resettlement might be reasons, besides being a 'Good Samaritan', which led their refugee neighbours to willingly take care of people who they did not have any familial ties with.

CHAPTER 5

Work in View of “The Life of the Hoe”

1 Case 7: Claire

Potatoes, a burnt hut and a special gift

In one of the villages, between a phone repair shop and a hairdresser’s, Abe was heaping up piles of potatoes in front of a storage room half full of them. Claire sat on a bench with her crutch beside her, talking to a man in a white *kanzu*[1] and a woman in a veil. Although it was World Refugee Day and festivities were taking place in another part of the settlement, Claire and Abe thought it was more important to keep their store open than to join in. Amani had told me the news that they now owned a shop, and I was eager to know what had taken place since the last time we met. Claire explained:

> After the time we spoke, I went to the offices of the UNHCR, the OPM, and the AHM, and they thought about me and saw fit to give me a gift. They gave me a bicycle and a phone. And they said they could find a way of supporting the children, so they paid the rent for this store for six months. […] They said, “you need to be an example for other women”. They had watched me and they thought I deserved that gift.

Before Claire was assigned the shop she used to trade potatoes and sometimes other produce in Kyangwali’s weekly market. Especially after she received this gift, I observed that she was a popular trader. Well-known people like the settlement commandant or the Ugandan manager of the Catholic guesthouse I was staying at bought potatoes from her. Once on a market day when Claire was resting on a sack of potatoes next to different-sized plastic basins and buckets filled with potatoes, I heard her laughingly advertise her new shop with the address, “ask for the woman with one arm and one leg”.

It seemed that Claire had assumed I had influenced how the aid agencies supported her, when she reflected on what had happened since we last met: “Those are the changes I saw and I said, ‘Oh, sure, Maria has given me a chance’.” The previous time we had talked inside a Pentecostal church that had offered Claire, Abe and their five children a place to stay next to the church

---

[1] A long white robe worn by Muslim men in East Africa.

building after their house had burnt down. "I think the house was burnt down because of business conflicts", Claire said, recounting that a fellow trader had threatened her for interfering with his business interests before her house was set on fire.

When I visited Claire one day in their temporary home next to the church, we prepared to visit Abe, who was clearing their former plot of land for a new hut. With her one leg stabilizing an iron pot on the cooking stove, Claire used her one arm to stir the porridge with a wooden spatula. Her second oldest daughter entered with her baby sister on her back and lay her down on the only mattress in the room. She then helped her mother serve porridge to her younger brother and I and poured the rest of the hot pulp into a jug that we carried to Abe.

While Claire used a crutch under her one arm to take small steps, Abe or her son usually carried her on the back of the bicycle for longer distances, as was the case that day. Yet Claire said that she was glad she had lost her opposite leg and arm, which allowed her to use a crutch more easily. She had been shot in 2008, when Laurent Nkunda's CNDP (National Congress for the Defence of the People) had rebelled against the Congolese army in North Kivu. She was three months pregnant with her third child at that time. Her wounded leg and arm had to be amputated immediately. She stayed in hospital for nearly a year and gave birth to her daughter Patricia by caesarean section. When she recovered, Claire was not willing to stay in the place she had been shot, so they decided to cross to Uganda.

When Abe took a break from work to eat the porridge we had taken him, we talked about an incident that had happened during a distribution session of soap and other goods for 'vulnerable' people in Kyangwali. Claire's name was not found on the list of beneficiaries when she reached the distribution point. Abe reasoned: "If they see that you have some business, they will not give you anything. And it not only applies for soap, it applies to everything else – as soon as they realise that you have some business and resources". During the rest of the interview Abe continued ploughing the land of the compound. Particularly when Claire talked about the assistance she had been denied by the organizations because she had an able-bodied husband, she raised her voice and gesticulated vigorously, including with the stump of her missing arm. This was the case for both food rations and house construction, and Claire expressed her fear that, without the necessary help from the aid agencies, Abe might leave her one day:

> I have no legs, I have no hands, so I feel bitter in my heart for sure. That is why I say I even despise myself a lot. But if I had my hands and legs, we

> would be like bosses. Because me and him [Abe], we would dig [farm], and everybody would be impressed about how we would do business. But we are now just getting left behind due to one hand [one person].

"In Congo, we helped one another a lot," Claire said, when she continued describing her situation. She was not only referring to her changed bodily state, but also to the better economic conditions there: "My life before in Congo was very good, because it was beneficial in business. If you went with 500 dollars, you would come back with another 500 dollars. In other words, the profit in Congo is very good and you can plan very well for your children". Claire continued the comparison by listing how much profit you could make from a sack of potatoes or charcoal in Congo, and how much of your children's clothes or school fees that would pay for. She added: "Everything was in the house, whether it was rice, *matooke*,[2] bananas, or potatoes. So you just had to prepare and cook it. Prepare and cook, without even knowing the life of the hoe … You know, in Congo, we did not dig [farm]. We came to know the hoe here".

Despite these challenges, and due to the special gift Claire had received from the aid agencies, business in Kyangwali was going pretty well. When I visited the family some months later, a new hut plastered with sand, and with a corrugated iron roof stood in the compound. The land around the hut was cultivated with onions, cabbages and *greens*,[3] and there was even a shelter in which Abe had started to grow passion fruit. After Claire had shown me around the new hut, with the noisy children running around us – even the baby girl had started walking in the meantime – she called one of her daughters to show me her excellent report from her second year in primary school. Then the boy came with a T-shirt in his hand and Claire helped him to put it on, using her mouth as a support. As usual, Claire spoke in business terms, telling me that she had been able to buy the children clothes for Christmas with the profit from selling a sack of potatoes.

As we had initially planned to check the current status of their resettlement case, I had taken my computer along on this visit. Claire and her family were eager to know in which US state they should imagine their future life, but it turned out that Claire had left the papers with the log-in details on at her brother's place. It was only recently, when we had started talking about their resettlement case more, that I had even found out Claire had a half-brother in Kyangwali. Until then I had only known that she had siblings in Congo who she was no longer in touch with. Claire and I lost contact when they finally moved

---

[2] Green bananas, also called plantains.

[3] *Greens* is an umbrella term used for different types of green leafy vegetables.

to the US. It was only when Martin (case 9) showed me pictures on his phone of Claire and Abe posing in caps and sunglasses, that I learnt they had settled in New York.

2 Case 8: Ignatius

The shop, the shop and a prosthesis

It was always difficult to have a long conversation with Ignatius or conduct an interview with him. Except for when he was in church on Sundays, he was always to be found in his shop in the centre of one of Kyangwali's villages. Again and again, once my eyes had adjusted to its stuffy dimness, I was surprised by what the small place had to offer. The shelves, reaching up to the ceiling, were crammed with labelled cartons of soap bars and salt, jerry cans and bottles of sodas like Mirinda, Stoney and Novida, some of them covered in layers of dust. The wooden counter was full of transparent containers with coloured lids that held chewing gum and other small sweets wrapped in sparkling packaging. In other boxes and half-open bags were *mandazi*[4] and buns, behind which you could see locks, razor blades, sugar, tea, matchboxes, schoolbooks, toothpaste, liquor in plastic bags, candles, pencils and cigarettes. Spices and washing power, plastic bags of all sizes, jugs, mugs and handkerchiefs hung from the ceiling. I could drop into the shop for a chat at any time and, depending on whether one of Ignatius's children was around to take over some tasks or not, we would find more or less time to talk. Yet, mostly there was a constant stream of customers, who Ignatius helped find the right products and coins for change by torchlight. In these situations I sat down on the small bench in the shop and drank one of the sweet, sticky sodas that Ignatius usually offered.

While Ignatius worked fast and was outstandingly attentive in serving potential buyers as quickly as possible, it was difficult to say if his slow steps and the laborious movements he took when reaching further into the shop were due to his advanced age or the leg prosthesis that pained him. During one of the less busy moments when I was visiting Ignatius, he took a plastic bag down from a shelf and fished out an exercise book, pulling two photographs out from between the pages. One showed him with two crutches and one of his trouser legs tied up at his amputated knee. The other one showed him in the same posture, though with his youngest son, who was ten at the time of my research, standing next to him. The photos had been taken two years

---

[4] A snack of sweet fried bread.

earlier when his old, broken prosthesis had been replaced at Mulago Hospital, the national referral hospital in Kampala. Ignatius never told me much about how he had lost his leg, only that the Red Cross had taken him to hospital in Uganda, across the border from Bunagana in Eastern Congo, where he had been shot. One of his sons had found him in the hospital, and they had stayed at the border transit centre before coming to Kyangwali.

Referring to the photos, Ignatius explained that he had been given the second prosthesis by the service providers in Kyangwali. The doctors at Mulago had told him that he should refrain from walking around, and continue using his crutches to avoid more pain. While he really only walked around his shop during my fieldwork period, he used to travel using a tricycle he had once received from a donor delegation that had visited Kyangwali. Although the aid agencies did not replace this tricycle when it broke down, Ignatius maintained his overtly sympathetic attitude and gratitude towards the service providers: “They took very good care of me. They gave me all the necessities that I needed at that moment, and I am not in too much pain, the way I used to be. Life is a little bit better now”.

Whenever Ignatius expressed his attitude, he emphasized the importance of the support he had received from an Italian aid organization that used to operate in Kyangwali. More than once, they had given him a loan to start his shop and to continue investing in his business. He said:

> The loan is what made a big difference, it was my life changing support … Any loan that I got, for example I got 500,000 Ugandan shillings,[5] I paid the interest and paid back their money. Even now, the good state I am in is because of the loan and I would wish to get more, so that I can continue in this line and expand what I have.

Although he had received the loans a long time ago, they had still enabled him to afford a good education for his children up until the present day. Four of his six children were of school age and attended boarding schools in Hoima, the nearest town to the settlement, and the reputable Coburwas primary school in Kyangwali. Thanks to her solid education, one of Ignatius’ elder daughters was now working for the UNHCR as a translator.

I never met Ignatius in any other environment than in front of or inside his shop, although the house where he lived with his family was right behind it. From time to time the shop’s back door would open and one of the older

---

[5] Approximately 130 US dollars.

children would come in and pick up some washing powder or a matchbox, or one of his grandchildren would peep through the open door and vanish immediately when I waved at them. Ignatius' youngest son was most often in the shop with him when home from school, helping him to lift a box of soap bars from the shelf, or running to another shop to look for a supply of the popular *airtime* vouchers, or money for change. Ignatius told me about his reunification with his family in Kyangwali: "[They] found me here. I first came here in hardship, with my life in jeopardy. I came with one son who was very young. My wife and other children joined me when we had almost forgotten about them, three years later". This had been in 1999 but, even surrounded by his family, Ignatius described his life back then as one of hardship: "We used to suffer a lot, because I depended on the garden and my family. And you know, with those things from the garden, you only get to harvest when it is the season. We did not have anything else to depend and rely on. We had to survive on the yields from the garden".

It was his wife, sons and daughters who were cultivating the land. Yet, it was not only the dependency on agricultural outputs, but also the changing land issues that had made Ignatius change the focus of his livelihood. He explained:

> The problem is that the number of refugees is increasing. I used to have about five to six gardens that they [the service providers] gave me, but when our relatives [referring to other refugees] came, the gardens were removed from us. I have no control over the UNHCR, since the land is theirs. So when our relatives came, the land was taken from me, and that is the reason I decided to sit here [in the shop].

When I dropped into the shop during my last visit to Kyangwali in January 2017, I was surprised to find Ignatius gone, and his married son behind the counter. The shop was somewhat emptier, but also more organized and cleaner than before. I knew that Ignatius and some of his family were in the process of resettlement, so I was happy to hear that their opportunity had come. The last time I had talked about resettlement with Ignatius, he had shared his hope that I would visit him in the US. He hardly believed me when I explained that Uganda was much nearer to my home than America.

∴

Walking through Kyangwali during harvest time was an experience in itself. In the daytime, the villages were empty and quiet, the houses locked. People with disabilities referred to life in Kyangwali as "the life of the hoe". Allocating land to refugees to farm was the core of Uganda's self-reliance strategy and thus for people's livelihoods in the refugee settlement. Yet, self-reliance through agriculture did not provide the same possibilities for all. By assuming that every refugee was willing or able to do agriculture, this approach completely excluded people with disabilities and others who were unable to farm from the overall aim of self-reliance. Nevertheless, land was a crucial resource for most disabled people. As in the cases of Ignatius and Claire, family members usually cultivated the land. Other individuals hired labour to cultivate their fields, and a few did some of the work themselves.

Although the 2006 Refugee Act gave refugees the right to work in Uganda (Hovil 2007) it was, in reality, a tenuous possibility in Kyangwali. Compared to people in town, the camp residents lacked any spare money to spend on things such as hairdressing, having their nails painted or signs designed, disabled people told me – so there was little opportunity to establish businesses providing these services. From a legal perspective, refugees were free to move outside the settlement as long as they could prove that they could be self-sufficient. Yet moving to a city would mean paying for rent, whilst ceasing to receive any more food rations and other aid.

According to the Oxford Dictionary, the word 'livelihood' signifies a means of securing the necessities of life.[6] As I never used the term 'livelihood' in my conversations with people with disabilities, I do not know which Swahili expression they would use for this. Yet, when we discussed life and work in Kyangwali, much of the talk involved more than 'securing necessities'. After the incident when Claire's hut was burnt down, she lamented:

> You find the life we are facing here is a very bad life, it is a life of bitterness. Even if you are blessed and you have your project, you find one comes and cannot be happy for you, and you find you are just going backwards instead of going forwards. So I've come to find that here it is not possible for someone to develop and change their life like in Congo.

The way Claire spoke about a "project", of "going forwards", to "develop" something that would "change their life" reminded me of the ways Livingston talks about "building" and "self-making" for all kinds of investments in projects like

---

[6] While in Old English it was composed of *lif* (life) and *lad* (way, course), meaning 'course of life', in the 16th century the word's meaning changed to 'means of keeping alive' (Oxford Dictionaries 2018).

building families, houses, or businesses (2005, 15). Disabled people expressed the essential aspect of work in terms of providing for a family, arguing that the focus on agriculture did not give them a fair chance to invest in "building", as Claire argued: "You see, a disabled person cannot dig [farm]. So you find the life of disabled people's children is wasted … Even though I am disabled, my children should have an education. I cannot get the resources to take them to school and clothe them". Thus, disabled people's exclusion from agricultural livelihoods meant that their possibilities for self-making were undermined.[7]

In light of these restricted opportunities, this chapter looks at how the aid agencies approached disabled people's exclusion from their livelihood approach, and tackles what this meant for their lives in the refugee settlement. First, I discuss the rationales by which the aid agencies considered disabled people unable to pursue agriculture, and what alternative solutions they offered in their livelihood approach towards them. Second, I demonstrate how and why disabled people challenged this approach, arguing that – rather than any sensitization or training they were offered – it was financial and material contributions that made a genuine difference to their lives.

Despite the focus on agricultural livelihoods in Kyangwali, disabled people found manifold ways to be economically active. Like Claire and Ignatius, they engaged in different forms of trading, electronics repairing, tailoring, bicycle mending or tobacco bundling in and around Kyangwali. Yet, as Claire had experienced, this was at times contested. Therefore, I will thirdly, examine the tensions that emerged between vulnerability and self-reliance. Finally, the concept of self-reliance will be interrogated in the context of a refugee camp, taking people's connectedness into account. In regard to the fact that Ignatius' and Claire's businesses were somehow doing well, I argue that self-reliance in some cases might even have been more possible for disabled refugees, who had fewer kinship ties and who received aid on a regular basis, than for people trying to make a living within dense family webs and without access to aid.

---

7 Devlieger demonstrates in the context of Congo that earning an income "provided possibilities of sexual relations, marriage and children that were previously considered unthinkable for disabled people" (2018a, 163). Livingston observed the economic changes in Botswana that increasingly put education centre stage, diminishing the importance of physical strength and ability as needed in agriculture or mining work. She argues that this brought significant changes for people with various kinds of disabilities, as their intellectual skills increasingly became more important assets than bodily capabilities within the world of work and income (2005, 12).

3 Bridging the Gap: Skilling People with Disabilities

The restrictive focus on agriculture had led to the service providers' assumption that disabled people were vulnerable in terms of work. Dolores, an aid worker from AHM, stated:

> Those [disabled and chronically ill] are the people that fall into that category [of the 'vulnerable'] – those who cannot dig, but also those who cannot move to Kampala or reach Hoima [the biggest town near the settlement]. People do all types of business, and the more mobile you are, the more you are exposed to this business world and you get opportunities for trading. You find people are able when they have business skills, you find they do not beg for food.

Dolores explained that it was a considerable challenge for disabled people to venture into business as a substitute for agriculture, due to their limited mobility. Her explanation not only pointed to the challenges of pursuing business in Kyangwali, but also implied how the problem of this restrictive focus on agriculture could be solved, by arguing that, if people had the right skills, they would not beg for food. It was during one of my first visits to Kyangwali that I told an aid worker about my research and heard something similar. This person recommended I should focus on the question of why, despite all the support the aid agencies provided, people with disabilities were not becoming self-sufficient and were still dependent on aid. On the one hand, Uganda's refugee policy was based on a development-oriented approach that highlighted the idea of self-reliance and empowerment. On the other hand, people with disabilities were approached through the prism of needs and according to their vulnerability. Thus, the aid agencies' categorization approach to vulnerability did not mean that people with disabilities were ultimately exempted from the self-reliance strategy (Clark 2007, 289; see also Bakewell 2003, 13).

An aid worker told me, in relation to this: "You teach someone to live without you, because at some point you may not be there to help them. So you really teach them, you counsel them and tell them what they can do. And that is where my other colleagues come in to lend a hand on skills". According to this view, before people with disabilities were taught skills, they and the community ought to be made aware that they can work. In this way, the service providers' attitude and approaches towards disabled people was in line with the broader paradigm shift within humanitarianism, that promoted disabled refugees as being empowered and capable actors, instead of vulnerable and passive victims.

The aid agencies held personal responsibility very high in their attempts to promote disabled people's self-reliance, realizing that not just the individuals themselves, but also their families and the community at large needed to be informed about this. An AHM aid worker reasoned: "Most of all, the families need counselling. They need to know that people with disabilities are not 'just there', but that they can do something for themselves". The organization Aid Global also proudly laid claim to the statement that "disability is not inability",[8] and it communicated this value to a wider audience through its drama group. In one of their rehearsals they depicted the scene of a man begging, while people walked past him. One of the passers-by stopped, refused to give him money and told him to work instead of begging. Later on in the play, another person taught the disabled beggar how to mend shoes, after which he happily started earning his own money.

An AHM aid worker, who offered psychosocial support to refugees, also pointed out: "We have our motto that 'disability is not inability'. So whatever you do they can do, they have families, they have children and they have to support their families". She told me about her individual counselling through home visits and focus group sessions. The 2014 report on AHM's support for people with disabilities noted that "293 home visits to 183 (M96, F87) PWDs [were] conducted and psychosocial support ensured".[9] I was surprised by this number, as none of my interviewees knew about psychosocial support or said they had ever received it when I asked them. It could have been a coincidence that none of my interviewees had ever been in contact with a psychosocial counsellor. Yet, it is also possible that they did not consider a psychosocial counselling session comprised 'support' or 'assistance', which they referred to with the Swahili word *msaada*.[10] The approaches taken by the aid agencies implied that they defined dependence and ignorance as the problems disabled people in the camp faced, rather than a lack of goods or cash. Consequently, instead of direct financial and material assistance, they saw the solutions as being training and sensitization sessions. The ways these approaches were contested by my interlocutors is discussed in the next section.

---

[8] Aid Global, project brochure, 2015.

[9] Africa Help Mission (AHM), PWD Report, 2014.

[10] That they predominantly thought of support as something material or financial also became apparent when people with disabilities said that they did not receive any support from neighbours, even though they fetched water or hung up clothes for them.

4 The Essence of Aid Projects: "You Can Only Remember What You are Given"

When I once asked Muriel (case 3) what she remembered from the meetings she had had with Aid Global, she first reacted questioningly: "What they told me? Most of it I have forgotten". Amani encouraged her, "just what you can remember", to which she responded, somewhat sharply, "you can only remember what you are given". This statement reflected a widespread weariness of the great number but limited relevance of training sessions and workshops among the people I interacted with. It was not uncommon to reach a village and see a group of people sitting in a circle with an instructor talking about seasons and seeds, or to come across laid-out clothes patterns, sewing utensils or plastic heads with wigs from the diverse livelihood programmes. The notion that "you can only remember what you are given" indicated what disabled people perceived as the essence of these livelihood projects, and how this stood in stark contrast to what the aid agencies had to offer.

Some long-awaited handicraft training implemented by AHM exemplified certain aspects of the different views on this matter. The training took place over two three-day sessions for two different groups of people with disabilities, and was led by instructors who came from Kampala.[11] St. Patrick's Catholic church room was silent when I entered, while people with various disabilities concentrated on their work of making bracelets, handbags and sandals. I was surprised to see a good number of my interlocutors in the training, although they had earlier complained to me that such training sessions were a useless waste of time. Many of the workshop participants had learnt some kind of handicraft at one point in their lives, and knew perfectly well how to work with needles and scissors. This was the case for Adam, who had learnt tailoring in Congo and was a practicing tailor in Kyangwali. He shared his opinion with me that three days' training for different handicrafts was not enough for people who were learning it from scratch, and that there was a strong risk that people would forget their newly-learnt skills if they did not have the materials to continue practicing afterwards.

---

[11] The instructors had been selected beforehand by AHM, based on different tenders. Like some of my interlocutors, I was surprised that AHM chose to bring non-disabled trainers from Kampala, instead of working with people with disabilities who lived in the camp, like Vitali (case 5) or Jacob (case 4) and many others who had an immense knowledge and advanced skills in various kinds of handicrafts.

When I was informed about this livelihood training, materials and capital were said to be included in the budget. They would be given as starting kits to groups of people with disabilities after they had completed the training. But by the time the training took place, there was not enough money to cover starting kits or any longer-term involvement of the participants. Scarlett, the project’s initiator, told me:

> Since 2012 I have been pleading to realize this crafts training. And now it has happened, just because of extra funding … I am so happy that this training was successful, when I saw that people were skilled and could do something, when they produced shoes and bags. So now we are still waiting for the start-up kits.

On the day of the training I attended, the people I talked to were informed that their start-up kits would not arrive until later, when the aid agencies had the money available. Unfortunately, the anticipated materials did not arrive during my fieldwork period and had still not turned up by my last visit to the refugee settlement in January 2017, more than a year after the training had taken place. It was not clear to me why the handicrafts project for people with disabilities had come to a halt – whether subsequent project proposals requesting the materials had not yet been written, or whether the project’s continuation had not been approved. Scarlett was already concerned about the UNHCR’s authorization shortly after the training: “We just had the experience in this workshop that most of the material was stolen. We provided needles and other things for the groups, but the people don’t have the mindset for teamwork, so many just put them in their own pocket”. Scarlett expressed disappointment that the project was not likely to continue: “The biggest issue will be whether we get the money approved for the items. And here, the challenge comes in that the materials have been vanishing. Because when it comes to reporting, we are the ones responsible”.

Disabled people were also disappointed when the promised materials for production did not turn up. “They told us they would bring us tools to use in March, now we are in May,” said a disabled woman, which led her, like many others, to question the purpose of this training that ultimately did not change anything for them. My interlocutors felt especially offended that they were not allowed to take home the sandals, purses, bags and bracelets they had produced during the three days. When one participant railed against the aid agencies’ mistreatment of people with disabilities several months later, he brought up the fact that they were prevented from owning the nice things they had produced, saying “they even took away the shoes we made” – it simply did not make sense to him, and to many others. Because it did not enable people to develop anything out of it, over time people with disabilities judged this training to be anything but successful.

The different feelings of hope and possibility, but also disappointment and mistrust that evolved around this handicraft training revealed a lot about the differing understandings that people with disabilities and the service providers had about support in relation to livelihoods. Such feelings were also at stake in regard to Aid Global’s project. One of my interlocutors explained: “They [people from Aid Global] told us that we could gather as disabled people in a group, that we could exchange ideas and see which thing can help us. They said we can knit, do hand work, sewing … but when it came to any help, nothing. It all needs capital. If we could get money, we could use it, but nothing”.

The claim that training without materials was not of much use to start an enterprise was also evident in Vitali’s (case 5) concerns, when he argued: “You see, they [the aid organizations] may come and teach you, but there is a proverb which says, ‘when you give a person a fish, you should also give him a fishing hook’. They come and teach us, but they don’t give us materials. I have hands and skills. If they gave me work, I would work”. The proverb that Vitali deployed represented one of the many critiques of the slogan “Give a man a fish, and you feed him for a day. Teach a man to fish, and you feed him for a lifetime” (Ferguson 2015, 35). This slogan stands for the prevailing belief that “the object of development work is transformation, not charity, and that recipients of aid should get productive skills and the opportunity to work, not hand-outs and dependency” (35).

Investments in training, sensitization and advocacy were broadly considered the best solution by aid agencies in the camp, as these approaches were in line with Western ideals of equality and independence and a development discourse that promotes empowerment and sustainability (see also Scherz 2014, 44). Hand-outs or ‘giving a man a fish’ instead of ‘teaching him to fish’, is considered as keeping people down in dependency. Vitali’s and many other disabled people’s claim for materials confirmed that they would not be likely to fall into more dependency if they were given a real opportunity to work. Yet the aid organizations insisted on ‘teaching them to fish’, despite the fact that most of them already knew how to fish perfectly well.

Especially within AIDS work across the African continent, Swidler and other anthropologists have observed an extraordinary interest in training and workshops, as these events created opportunities for extra income for participants (2009, 200; referring to Lwanda 2000; Smith 2003). This results from the fact that participants in these kinds of activities usually receive cash allowances for attending. Furthermore, these activities provide important networking platforms for the workshop participants. To elaborate on this, I will draw on what Ferguson calls ‘distributive labour’. With this concept he grasps the important and valuable social activity of making distributive claims on patrons (2015, 97). It describes the long and difficult efforts of positioning oneself as a beneficiary, and of managing to be distributed to.

When people with disabilities in Kyangwali went to workshops, attended meetings and took part in training sessions, they were engaging in distributive labour. Beyond their hope of gaining new skills and knowledge or certain hand-outs, their presence in workshops was also about cultivating relationships through which they hoped to find out about other, possibly more beneficial, events and opportunities.[12] Yet, in many cases, disabled people in Kyangwali did not receive a fair return on what they had invested through their distributive labour. They were clearly informed that there were no allowances for participating, but they hoped for at least some other kind of contribution, to enable them to start doing the activities they had been counselled about and trained for.

Paradoxically, people were encouraged to express their needs, to share and list their ideas about what would help them the most. People’s priorities for direct livelihood assistance also came to the fore during the aid agencies’ annual participatory assessments, which aimed to give people a voice in the organizations’ planning for the next budgetary year. Yet, once these so-called ‘needs assessments’ were done, there was no meaningful outcome for people with disabilities. People’s participation in projects were not about priority setting, but seemed, above all, to reassure the aid agencies that empowerment was being promoted – an activity that found its way into reports accounting for these projects’ success. This all points to the fact that “participatory approaches to sustainable development often fail to match local expectations concerning the various exchanges involved” (Scherz 2014, 145–46).

Another challenge to the livelihood projects I came across in Kyangwali lay in their neglect of the fact that a skilled fisherman not only needs a fishing rod, but also enough people to sell the fish to. When I talked to Scarlett before her handicrafts training for people with disabilities and asked whether she already had any ideas on how to market the crafts they would produce, she answered: “It is still a pilot project, so we will start to find buyers among the organizations

---

[12] It was thus also possible for more people to show up for certain events if word had spread that I, a European researcher, would be attending a livelihood group meeting, since my presence was assumed to bring along the potential of additional resources, or at least connections to institutions and donors.

themselves. Then we will see how we can expand". Even though Scarlett, like other aid workers, seemed well aware of this challenge, it was not prioritized during the project planning.

This was also the case for a soap-making project that highlighted the fact that it was 'inclusive', having disabled people as members, including Camille (case 6). While the members of the soap-making group had to meet many times for the administrative tasks of setting up and registering a group, the liquid soap was produced in a few hours, once the materials had been provided by the organization AHM. The group's members used the soap for themselves, but it soon became clear that there was not really any money to be made out of this business idea. While AHM's demand for soap for their offices had been satisfied immediately, it seemed that refugees preferred to buy the tried and trusted Omo and Star Soap washing products, which were available in every small shop in the camp. The group dissolved a year after its initiation. For Camille, who had walked there or drummed up money to travel to Kyangwali's centre for the many meetings in advance of the actual soap production, and who had contributed her registration fee to the group, the result was disappointing.

Any kind of livelihood support provided by the aid agencies required people to form groups, which meant that they had to spend time and money to take part in seemingly endless meetings. Forming a group also entailed appointing a group leader. One of the aid agencies supported a livelihood project for disabled people, which had been proposed by Richard. Richard had no disability himself, but was engaged as a community mobilizer for Aid Global, and carried out many jobs in cooperation with AHM and other organizations. When Richard created a group of 25 people that he and his wife trained in handicrafts, some of my interlocutors still associated Richard with Aid Global, even though the organization had left Kyangwali by then. Mistrust grew among disabled people who were not involved in the group, who alleged that Richard was "eating their money" and that he prioritized people with disabilities from his own villages – or even non-disabled people he knew – to profit from the resources. This led disabled people in the camp to conclude that, as well as having the right skills and possibly a market, they also needed to gain access to the people that channelled such resources and opportunities, in order to benefit from the aid agencies' initiatives.

Another facet that impeded endeavours in terms of disabled people's livelihoods was the aid workers' and agencies' own limited access to funding. Providing income-generating support was beyond the scope of Aid Global's project, as it was about giving people access to water, sanitation and hygiene. It therefore could not fulfil the demands of disabled people in regard to their livelihood opportunities. Moreover, the requests that were most prominently raised in the aid agencies' participatory assessment in 2015 – for direct, if possible monetary assistance for business projects or support for their children's secondary school's fees, were unlikely to be met.[13] They were simply beyond the aid organizations' remits and funding guidelines. Livelihood and secondary education were not one of the five basic needs defined by humanitarian actors: food, shelter, health, water and sanitation, and primary education (UNHCR 2013: 38–42). So, even though the service providers in Kyangwali and Uganda were increasingly moving away from emergency aid towards development assistance, their actual focus on livelihoods remained very limited. The UNHCR had difficulties in seeking funding outside its remit of providing emergency humanitarian assistance and resources to enable development. There was not much fish to be caught for the aid agencies themselves in terms of livelihoods.

Despite the challenges involved with livelihood groups described above, the aid agencies prioritized giving livelihood assistance to groups rather than individuals. When I asked Scarlett if AHM would also consider individual livelihood support, she answered:

> We have not yet reached there. Because this is also where the challenge comes in. We have for example been supporting PSN girls, girls who have dropped out of school, with *kitenge* cloth for individual support. A few sold them and continued with their business, but many others just chewed the money after selling them.

'Giving a man a fish' was considered risky due to the assumed irresponsible behaviour of the individual aid recipients. Conversely, Muriel (case 3) saw it like this: "These group things are not good because we all have different things we want to do and some could eat the money. But when I get money, I know what to do with it." The idea that people themselves know best how to invest money sustainably for their own lives resonated strongly with the approaches of direct cash transfers in and beyond refugee settlements, and has been proven in a number of pilot projects (e.g. Kopf 2016). Despite this, the Italian aid agency that supported Ignatius remains the only organization in Kyangwali that handed out cash as a form of individual livelihood assistance, even though it was distributed as loans.

When people praised a certain project, they described the tangible things it had directly provided. They mentioned Aid Global's assistive devices or the

---

[13] As I was not able to attend the assessment, this information is based on an interview with the person who compiled a report of this assessment.

toilets that had been constructed for them. I was astonished by how many of my interlocutors lauded Aid Global's workshops for providing food and drinks, and compared them to other workshops in Kyangwali that did not include such amenities. Many people also told me about the clothes they had been given by Aid Global. It took me a while to understand that the organization had not distributed clothes in the form of an aid intervention as such, but that people with disabilities were talking about the orange hats and promotional T-shirts with the slogan, 'Together we can promote the plight of PLWD [people living with disability]' that were produced specifically for the celebration on World Refugee Day, as well as for other similar events. From the way people with disabilities talked about Aid Global's project, it became clear that, for many individuals, material benefits mattered most.

For Claire and Ignatius, as well as for other disabled people, it was generally material or financial support that made a difference for them and their families. Claire's business was doing well, especially after she had received the gift of rent for her shop and a bicycle that meant she could save money on transporting her products. Ignatius' case exemplified what difference more direct assistance such as access to a loan could make for earning an income on a sustainable basis. Camille (case 6) was only able to restart her business in the market after her money had been stolen when a friend from Congo gave her 30,000 Ugandan shillings.[14] This was also the case for Odongo, who had only been able to commence trading goods like cigarettes, sweets and soap, which he transported from place to place on his tricycle, when a friend visiting from Sudan had given him 250,000 Ugandan shillings[15] as start-up capital.

It was these material or financial contributions, much more than the training sessions offered, which people were able to make something out of, to sustainably invest in their families. Therefore, asking for material or financial contributions did not, in fact, reflect any kind of dependency resulting from laziness or an unwillingness to work. This insight reveals how people with disabilities and the service providers had a different, even opposing, understanding of what sustainable aid is. While aid agencies perceived hand-outs as being the opposite of sustainable aid and as creating dependency, they were actually what made aid meaningful for people with disabilities in the longer term.

---

[14] Approximately 8 US dollars.

[15] Approximately 68 US dollars.

5 Tensions between Vulnerability and Self-Reliance

During my interview with Claire and Abe, they told me about that incident when Claire was refused soap, oil and salt during a distribution session. I explicitly asked Claire about this incident after I heard from Bernadette, a friend of hers, who told me:

> So I went, and I met Mama Patti [Claire] there. They were giving soap, cooking oil, a kilo of sugar and a sachet of salt. I also said, let me go there. When Robert [an aid worker] saw us he said that we were not people to receive soap. They gave it to others, but me and Mama Patti were denied. They told us that, in our status, they see us as not among those who should beg for soap! He said that for us, we do business and we have money.

Both Claire and Bernadette were seen as undeserving of this special aid for 'vulnerable' people, due to their business activities. Any kind of social welfare system usually incorporates some sort of means-testing mechanism to determine entitlements, and with this comes the widely held fear of dependence – the worry that people might become less motivated to work if they can benefit more by earning less.

Even though Claire and Bernadette's examples seemed to be the exception rather than the rule, the fact that having an income or productive work was set down as an excluding criterion in the written guidelines for identifying 'vulnerable' people made this issue an unpleasant matter of uncertainty and created quite a paradoxical situation.[16] This became most obvious to me in Claire's case. Claire had been selected and especially rewarded for being a role model, as a refugee woman doing business well. In consultation with the various aid agencies in Kyangwali, the UNHCR had decided to buy her a bicycle, and rent her a place in the settlement's economic centre, as well as give her a phone. An aid worker, Dolores, also admired her for leading as a positive example for others: "She goes to the market even if the truck there is very high – she will use one hand, she goes up selecting the good potatoes, puts them down, then she sits and starts selling her potatoes using one arm … It is a very good life example I have seen". Even though Dolores did not explicitly say exactly what

---

[16] One of the tools used to identify EVIs and PSNs in Kyangwali (called 'EVI/PSN verification criteria') describes a person to be included in the categories as "Disabled with no family support and no income generating activity".

Claire stood for as an example of, her further elaborations lauded her as a hard-working woman who took responsibility for her family. This was also reflected in Claire's narrative, when she explained why she had been given this special attention and support:

> They would first inspect and see that the work I do is giving them encouragement. They saw that I was putting in effort and would even go to the market, struggling for the children. They realized that here in the camp it is those who are able who keep going to ask for books for their children, asking for several other things, but me who does not have hands or legs, I don't always go to the offices.

The service providers seemed to place particularly high value on people's individual responsibility to become self-reliant. This aspect also came to the fore through the interest they expressed in how Claire managed her savings and thought of reinvesting her profits, as she explained:

> They [the aid workers] asked "how much capital are you trading with?" I told them "two hundred thousand, as a sack of Irish [potatoes] is sixty thousand, that means two hundred is three bags including transport". So each of the bags, how much do I get? I told them if God blesses me well, it is ten thousand per bag. "Now what do you use the profit for?" I told them, "that profit, when I get that thirty thousand, I look into the house, I have no charcoal, I buy charcoal for ten thousand, then I see there is no soap. I buy soap, now that is twenty thousand, and then my ten thousand I keep at home".

The fact that Claire was singled out from others as a good example of a successful businesswoman and responsible mother matched well the paradigm shift in discourse about refugees with disabilities. The focus on entrepreneurship reflected efforts to counter a tendency to victimize disabled refugees. This approach advocates that, instead of relying on a portrayal of their vulnerability, attention should be paid to the agency and competences of disabled refugees (Mitchell and Karr 2014; Pearce 2013; WRC 2014). I often observed situations where aid workers praised economically active refugees and criticized people who were asking or begging for support. It was interesting that Claire referred to what she had received from the aid agencies as a "gift", yet, through being a "very good life example" of the promoted image of an economically active disabled refugee, she also gave the service providers what they needed for the exchange relations with their donors (see also Whyte et al. 2014, 65).

However, people with disabilities much more frequently complained that they were not truly being supported in their economic activities. Jacob (case 4) told me that he had once tried to mobilize fellow disabled people with the aim of teaching them all the different handicrafts he knew. He wrote a proposal for a training school that aimed to enable people with disabilities to earn their own money, but he complained that it had not even been possible to receive 100 Ugandan shillings[17] from the service providers for this initiative. Odongo, the man from South Sudan, had a similar story to tell. He had founded a group of disabled people which he applied for two livelihood projects for. The first was a proposed goat-rearing project, asking for 80 goats. Considering that one goat produces offspring twice a year, they would not only have enough food, but they could also sell them, he had argued. The second project requested support with ten grinding machines: five for maize and another five for rice. This would mean, first of all, that people with disabilities would not need to spend money on this service, and additionally would gain an income by charging other people for the service. Odongo submitted the proposals in 2012, but had not had a positive answer by 2016.

As well as feeling that they were not really supported to become economically active, the aid organizations' emphasis on individual responsibility created tensions for disabled refugees. They were aware that a 'good' beneficiary was considered someone who took responsibility over their own life instead of being dependent on the aid providers. Whereas in some cases and situations people were rewarded for their efforts in this direction, in others they risked missing out on crucial support. Depending on the situation, people had to balance between being vulnerable enough to qualify for support, and being economically active and becoming self-sufficient.

6 Dimensions of 'Self-Reliance' in a Refugee Camp

Ferguson uses the term "distributed livelihoods" (2015, 89) to demonstrate that, in fact, many people do not make their living by doing productive work. There is a large number of people – not only in southern Africa where his research was located – who depend on the income stream of others, as well as on social welfare.[18] So far, I have mostly discussed the missing relations of

---

[17] Approximately 3 US cents.

[18] Ferguson draws on the example of the United States, which is considered as rather welfare-unfriendly, to demonstrate that far less people depend on wage work than we commonly assume (2015, 89).

interdependence that refugees with disabilities find themselves in, and what kind of hardships arise in such situations, where it is no longer possible to draw on a large social network when in need of help – financial or otherwise. This also plays a crucial role in regard to work. Disabled people said it was difficult to carry out business without the possibility of borrowing money. One of my interlocutors contrasted her current situation with the way she had done business in Congo: "Because over there, even with the little money you had, you could still do some sort of business. When I didn't have enough money I would get loans easily to do something".

It becomes more important to earn a steady income once someone cannot rely on the support of extended family. Adam, who had a tailoring business, one day discovered that he had kidney problems and was supposed to go through a lengthy process at the AHM office, with referrals to Hoima and Kampala, in order to receive free treatment. But he explained that he simply could not stay away from work for several days. He argued that he needed to keep working to be able to support his children in school, despite his kidney problems. The familial connections he had in Kyangwali were his brother and his wife's niece, but there was no possibility of financial support from them: "There is nobody. Even my brother whom I have here has problems taking care of his family, so someone who has to take care of his family, how will he support me?" This example shows that, even when family members were around, they often lacked the same capacities and resources to support their disabled relatives as they used to have in Congo, where they had more regular income, a bigger business or more land.

Moreover, there seemed to be something different at stake. "Money does not stay with a person," as one of Ferguson's interlocutors explained the "distributive pressures" that households experience in the form of moral and social demands on any kind of income streams, be they from employment, old age pensions or inheritance (2015, 94–95). Social power through money comes with social obligations, and this interdependence among kin could become very burdensome at times. I observed in Uganda that, when business was going well, or when a person earned more than a meagre salary, it would not take long before they were called several times a week by worse-off relatives, demanding contributions for school fees, business investments, or help paying for medicine or hospital visits. It is not always morally reprehensible to neglect such claims within the workings of patronage, but they cannot be easily ignored (see also Durham 1995).

Bernadette, a disabled woman in Kyangwali, talked about this issue one day, saying that family and neighbours asked her for money when they knew she had done some good business deals: "Even now, they always come and tell me to lend them. And when I say that I do not have money, someone gets annoyed that I have denied him or her. But if someone comes and I have it, I can give her, I can lend her". Anthropologists who have dealt with such distributive flows in different African contexts observe how people often use business profits for pressing family needs instead of reinvesting in the business and that, in these circumstances, it is very difficult to save (Whyte 2020, 138; Ferguson 2015, 95). Even though this played a role in Kyangwali, it was also apparent that social networks not only meant less potentially resourceful relationships to draw on. Equally, it meant that other people were less likely to make claims on an individual for resources. With small households and no extended family around, distributive claims by kin seemed to be less prevalent. Claire and Ignatius were doing quite well economically, and both talked about their strategies for saving and reinvesting in their business. Ignatius had even managed to afford school fees for his older children in better schools outside Kyangwali.

For those who had more family members nearby, the situation appeared more difficult at times. This was the case for Muriel (case 3), with her alcohol selling business. A big portion of her customers were family, and Muriel told me one day that they often drank on credit: "Some of them drink for free when the liquor is here, and this has stopped me from getting more drinks [supplies] after that. When they drink on credit and leave a debt behind, they will never pay it". From this perspective, 'self-reliance' might even be more possible for refugees with fewer kinship ties, and for whom support was provided on a regular basis, than for people trying to make a living within a dense web of interdependencies with kin, and without regular support.

In an independent evaluation of a community services programme for Congolese refugees in Tanzania, Shelly Dick points out that Congolese people may not value 'self-reliance' in the same way as aid workers do (2002, 22).[19] Her interviewees argued that it was not common to be reliant on oneself in Congolese society, as individual strategies to manage life were always linked to those of extended families. One might question the validity of the concept of 'self-reliance' in any society, but especially in those where "distributive livelihood strategies are not simply a product of poverty and deprivation but instead rest upon a deep social logic that finds application at all social levels" (Ferguson 2015, 115). Yet, I would challenge this stance a bit. I frequently observed that people in Uganda saw their families' demands on their income as troubling. They felt that they worked so hard for it that they wanted to invest their earnings

---

[19] Betts et al. 2020 also criticize Kakuma refugee camp in Kenya, where self-reliance approaches exclusively targeted individual risks and overlooked the importance of social networks.

into their house and their children's education, rather than giving money to a relative to start a business, or to pay for their medical bills. Livingston writes about how the increase in wage labour in Botswana and the money it paid gave rise to an "uneasy, bifurcated sense of personhood" (2005, 4), one that had to balance the tension between individual personal efforts and successes and the importance of investing in social relationships.[20]

Disabled people's aspirations towards independence cannot be neglected, even more so against the background of the UN rights discourse around economically productive and independent disabled refugees. For Vitali (case 5), independence clearly meant working and earning an income. He looked back at his life and told me: "The good life ended in Congo. When we were working, we could just work hard to get paid and cover all our other basic needs, like sleeping well, clothes and food". When Vitali had been working for the Dutch organization *Atel de Zome*, he told me, he was not only provided with accommodation, food and a salary, but also had access to free medical care, and was given a three-wheeled French tricycle and a three-wheeled Honda motortricycle, plus a monthly fuel allowance. Vitali had certainly experienced both security and independence through the kind of work he did in the rehabilitation centres.

His perspective on the aid agencies, however, seemed to reveal another aspect of independence, as well. I remember when I left Vitali's place after an interview with him, which was one of the first I had conducted for my research. When writing up my field notes that evening, I realized that I found it difficult to understand how Vitali – like many other people with disabilities I subsequently talked to – on the one hand embraced independence in line with a sustainable development approach that focused on individuals' personal productivity while, on the other hand, he claimed that it was the aid agencies' responsibility to fully provide for him. He did not seem to mind receiving handouts from the aid organizations, and expected more from wealthy foreigners.

Jacob's case (case 4) revealed some similar tensions. He often argued that it was important for disabled people to become economically independent, and he had tried to achieve this by applying to run a livelihood project on crafts making. One day he told me that he worried about how difficult he found not being able to provide for his family as the "head of the household". He considered it was his fault if anything was lacking at home – there was no salt in the

---

[20] This is not to say that a sense of individualism did not exist before in Botswana, but Livingston describes how these tensions have increased, especially when young women started earning money and had to juggle between town life and supporting their families in the villages (2005, 4).

house at that moment, he said. He believed that, as a man, it was his job to provide for his family, and it was precisely on those grounds that he claimed more support from the aid agencies. What was at stake there was the ways that Vitali and Jacob simultaneously engaged with different forms of dependence and independence that were not mutually exclusive, but in fact supported one another. Any kind of income, be it through work or through aid, was vital to enable disabled people to provide for themselves and for others.

It is important to place these insights into a broader context. A lot of research on Uganda concentrates on how refugees contribute to their local economies, focusing on refugees' engagements with the wider economic structures of the host state (Easton-Calabria and Omata 2018; Jacobsen 2005; Omata and Kaplan 2013). Their common narrative asserts that, through diverse economic activities, refugees do not just become independent from aid, but they actually benefit the economy around refugee camps. What these studies often do not emphasize enough, however, is the fact that a great deal of these economic activities are actually fuelled through 'hand-outs' – not only are objects of humanitarian aid like jerry cans, soap, mats and clothes sold in the small shops and markets in Kyangwali, but the monthly assistance received in the form of food or cash is also invested in consumption or business enterprises (see e.g. Bakewell 2003, 11; Jacobsen 2005, 34). While refugees' opportunities to create livelihoods and work apart from agriculture are somewhat restricted in Kyangwali's rural area, every month resources flow in and boost the economy. The overall value of this should not just be measured in the financial and material resources themselves, but also in the kind of economic security they create, similar to a basic income grant (see Ferguson 2015).

7 Conclusion

This chapter started with the observation that many disabled people in Kyangwali were being excluded from Uganda's self-reliance strategy because it was based on agriculture. My fieldwork revealed that, despite this focus on agriculture, people with disabilities found manifold ways to engage in work. This, however, created paradoxical tensions: disabled people were lauded for and encouraged to do productive work, but at the same time risked missing out on crucial assistance when their enterprises were successful. The aid agencies' efforts to skill people with disabilities by offering them training and workshops turned out to be very contested. They actually missed the mark by trying to 'teach a man to fish', when what was really needed were not skills, but capital, equipment, and markets. Muriel's expression that "you can only remember what you are given" pointedly encapsulated that what people expected stood in stark contrast to what the aid agencies had to offer, especially when viewed through the lens of 'distributive labour'.

So people were often disappointed: when they attended training courses, but afterwards received no money or material to start a business, or when they were not even allowed to take home what they had created during the workshops. This was very paradoxical: on the one hand, disabled people were actually recognized in regard to their challenging livelihoods situation – for example, when they came together as a group and were asked to choose which income generating activities they would prefer to do, or when they were told in a workshop that they were capable as people with disabilities to do any kind of work or business. Yet, when it came to what they really needed, the funds were not available for livelihood support because of an aid organization's field of work, their lack of planning, or due to the fact that refugees were not trusted to use either individual loans responsibly or to have their own project proposals financed. In many regards, in the view of aid agencies and donors, 'hand-outs' entail the 'spectre of dependency' (e.g. Meth 2004), as they run counter to ideals of sustainability and empowerment. In this respect, the aid agencies' livelihood approaches seem, again, to have mainly met the donors' expectations, while the expectations of people with disabilities were disappointed.

While embracing the fact that everyone is dependent and that relations of dependence are a way to survive, especially for poor people, this chapter has shown that there are always different kinds of dependencies at play. While people embrace the idea of dependency in some situations, in others they despise it. Such different forms of dependence and independence not only co-exist, but are thoroughly entangled. The idea of a 'dependency syndrome' does not seem to hold up at all. Instead, it is the case that aid fosters people's independence in certain ways. Especially in a refugee settlement, where aid is provided on a regular basis, and where distributive claims from relatives are fairly absent, it was possible for some disabled people to develop their own economic endeavours, separate from "the life of the hoe".

PART 3

∴

CHAPTER 6

Disability as a Category of Difference

1 Case 9: Martin

Documents, human rights and the protection house

Martin had a special home in Kyangwali. Behind the small police station, a fenced compound enclosed two concrete houses with separate rooms. A uniformed police commandant scrutinized me critically, and told me not to open the gate for anyone, as people were under protection in this place. Martin sat in front of one of the rooms in a plastic chair, his legs stretched out on a wooden bench and a metal walking frame in front of the open door to his room. He listened to Lingala music playing from his radio, and showed me his glasses with a sigh. They had been mended with tape at the broken part in the middle and made it difficult for him to read. Martin apologized when he could not remember the English words he wanted to use during our conversation, so had to draw on French and Swahili expressions. I sometimes found it hard to decipher his words, but mainly because of his unclear pronunciation. One side of his round face was partly paralyzed, a remnant of a stroke he had experienced four years earlier.

Martin left Congo many years previously, leaving a wife and children behind, because he had been politically persecuted. He and his brother had traded cars from abroad in Uganda's capital after he fled his home country. He told me a long story, supported by a multitude of documents – often both originals and copies – which he carried folded up inside his belt bag. Showing me his travel documents, he emphasized that it was important for him to be able to support himself instead of being dependent on the UNHCR, even though he had been given refugee status when he was living in Kampala. He fished out several police reports for me to read while he recounted how his brother had been poisoned. Following this incident, which led to his brother's death, he told me that he had experienced a blackout when he was in court for his brother's case. This made him believe that he might have been poisoned, too. He had great difficulty in remembering exactly what had happened after that, but he felt that his memories were becoming clearer and clearer every day.

Martin did not agree with his doctors' diagnosis of a stroke, now unfolding a number of medical documents for me to have a look at. With a sharp laugh, he told me that Ugandan doctors did not like refugees, so would even write impossible things in their notes. Considering a stroke to be something that afflicted people with a mental health condition, he pointed out that he was able to reason, that he knew how to read and write, and that his mind was alert. Yet, what happened had not only impacted on his movements, leaving him with what he called one "dead leg", but had also caused him problems with his sight as well as motor difficulties with his arms and hands.

Although Martin managed to do few things on his own, he was dependent on assistance in his daily activities. An aid worker told me that he already had four different carers who cooked, cleaned and washed for him.[1] During my entire fieldwork period Martin lived in the 'protection house', as it was called by inhabitants and aid workers alike. From inside the compound one could see through the fence to the AHM offices. This proximity allowed Martin to have frequent exchanges with several aid workers: sometimes I would find him chatting with them in front of their office, an aid worker would bring him his food rations and give him a coin or two, or the medical doctor would visit him to inform him about his medication. His most important contact seemed to be a senior officer in the UNHCR. Martin often referred to her mediations to explain progress when his medicine was delivered, his transport to Kampala organized, or his resettlement files advanced further through the process. He eventually even managed to have electricity from the police station installed in his house.

During the course of my research, Martin was referred to Kampala for medical check-ups several times. Like any other refugee who was referred to Kampala for medical purposes from the various settlement locations, he would stay at the Medical House, which was run by an aid organization in Kampala, for days or weeks. In order to visit him there, I first had to be security cleared by the main office of the organization in charge in another part of the city. I soon realized that most of the aid workers in that organization were familiar with Martin's name too. Although Martin was seated next to a new walking frame still wrapped in plastic where I found him at the Medical House, he still used his old one when we moved into the shade of a tree in the compound for more privacy to talk. Martin moved very slowly, first placing the walker an inch in front of him, before following along step by step.

Martin told me about his challenges with the food in that place. He was supposed to take his medicine with food, and there were certain kinds of food he was meant to avoid for his health, such as salt and oil, but the Medical House's kitchen used those in their meals. He emphasized: "I have the paper, the recommendation from the doctors. If you just say this as a recommendation without a paper, they cannot accept it, but for me I have the paper from

---

[1] These arrangements, made by the organizations, were discussed in Chapter 4.

the doctors". Martin put a lot of hope in the effects of the right medicine. He imagined being able to walk, write and work again, and earn his own money once he had been properly treated.

Another time when I visited Martin back in Kyangwali, he was reading in front of his room at the protection house. He turned down his radio's volume and put his special reading glasses on an empty chair next to a pot of *greens* and a flask. Martin's physical condition had visibly improved since the last time I saw him at the Medical House in Kampala. His words were clearer, and he was able to read much more again. He gave me a book and guided me to find the page where he was shown in a photo. A section of this book profiled him as a representative of a human rights organization in Congo. In his black briefcase next to his chair he carried a letter from this and other organizations, including the Refugee Law Project that was affiliated to Makerere University, and a Swiss organization I had not heard of before. These organizations would help him leave the country due to his medical conditions and protection issues, he explained. Martin used to work as a human rights activist and lawyer, and his knowledge clearly helped him with his own case. He commented: "I know very many articles, I cannot mention all of them to you. The human rights, the UNHCR ones, I know the articles, I know my rights. It is my right not to stay like this! … The UNHCR has to help me and support me with eating, housing, everything. I want good treatment and good protection".

When Martin's health had improved significantly, the authorities planned to move him out of the protection house. For this purpose they had built him one of the houses for PSNs like they had for Jacob (case 4). During my last visit to Kyangwali in early 2017, Martin was waiting for his bed for the new house to be finished, which was also a service provided by the UNHCR. As it was my final visit, Martin asked me what I had taken him as a farewell gift. As I did not have anything to hand, I helplessly said, "memories". But, as he understood that to mean a memory card for his phone, I agreed to take him one the next day. When we left, a friend who had accompanied me joked indignantly about Martin's boldness. He admired his cleverness and imagined that at some point he would be demanding a cooker and a fridge for his new place from the aid agencies.

2 Case 10: Bernadette

The market, bullets and prayers

Bernadette had just returned from church and was sitting on a small wooden seat next to the cooking zone, where she was preparing *mboga*, cassava leaves, that filled the hut with an aromatic flavour. Due to the heavy rain we had arrived late, and I asked if she was still willing to tell us more about her life as we had planned. Without bothering about time she bent over to disappear into the second room of her hut, quickly returning with a wad of photographs. One of the pictures showed her on a bed in a hospital, wearing only her bra and with a cloth wrapped around her lower body. On her abdomen, a quadratic patch covered the area which bullets had been removed from after she was wounded. In an interview Bernadette explained: "Looking back at my previous life, things were so good for me but now, see what I am going through as a disabled person. When I was normal I was so energetic, I would do a lot of work. And my legs functioned so well. When I remember how normal life was, it gives me so much pain". Bernadette's eyes filled with tears when she recalled her physical integrity from earlier times and contrasted it to her current bodily problems. The pain was evident in her facial expressions, when she lifted herself up from the chair to collect something from the next room, or when she grabbed her crutch to move outdoors.

Despite the pain she often experienced, Bernadette was always busy and found it difficult to refrain from any kind of work. Her house was located right beside Kyangwali's biggest weekly market, and Bernadette made the most of this location. She rented the space in front of her house to friends selling handmade chairs or *kitenge* cloth. Her house, and especially her compound, served as a place where people stored their goods or poles and plastic sheets to erect their market stalls. On those market days Bernadette usually sat in front of her house and collected notes and coins from both Ugandans and refugees, handing out the key to the compound which she always tied around her crutch. As well as her customers, other visitors also frequented Bernadette's home. Some dropped in to rest a while and chat, others to rearrange their goods, or to leave a baby behind to sleep for a while. Many people called her *shanga*, or *shangazi*, the Swahili word for 'aunt', which Bernadette explained was an expression of their good relationship with her. Before visitors, myself included, left her home in the evening, she prayed for and with them – a practice she also engaged in when someone she knew lay ill at home or in hospital.

Although Bernadette had arrived in Kyangwali on her own, over time she had found more and more people she had familial ties with, and she introduced people we met in the market or on the village street as a distant uncle, a cousin or a sister-in-law. The most surprising and incredible incident for Bernadette, however, was when she met Priscilla, her brother's daughter, who only lived a village away in Kyangwali. Bernadette used to take care of her like her own daughter after the girl's mother had died. Bernadette explained that many families had already been torn apart and scattered across Congo during the long years of conflict. While many people had fled the country, Bernadette had stayed with her family, not willing to leave: "We could move somewhere very far, and this is how we managed to stay in our country, running up and down, thinking the war would come to an end". However, her husband and two of her children died in this war. She remained with two other children, but they also disappeared when they had to flee again and she continued looking for them until she was injured. She recounted: "At that moment, I realized that my children were lost, my other children had died with my husband, many relatives had died, so that is when I decided to run and this is how I found myself here".

During one of the market days, after a torrential downpour had interrupted the traders' activities, I took shelter in Bernadette's home along with Camille (case 6). The house was squeezed full of people sitting and standing in the dark room, waiting for the rain to stop. Among them I recognized Claire (case 7), and Bernadette told me that they knew each other from the meetings that were organized by Aid Global. Although Bernadette was very critical of, and eventually disappointed by Aid Global's services, she emphasized that the organization had united people with disabilities and encouraged them to be more self-confident about their abilities: "They [Aid Global] are the ones that brought us together, they really assisted us so much. They talked to us about being disabled. They said we should not break down because we are disabled, being disabled is not a crime. You can be disabled and still be intelligent!" Bernadette had been in much better health when she arrived in Kyangwali, being able to walk longer distances and do more heavy work. However, one day in Kyangwali she was attacked by a cow and injured again, and since then her physical condition had worsened and she started to feel a lot of pain in her back and her leg. She was taken to Mulago Hospital in Kampala where she was issued with a report that stressed the necessity of treatment abroad.

Bernadette often told me how difficult it was to obtain the medicine she had been prescribed in Kyangwali. As medication was frequently not available in the health centres and was too expensive to buy in the privately-owned pharmacies compared to her home country, she sometimes tried to arrange medicine with travellers between Congo and Uganda. Bernadette believed that she could heal with proper medication, and this is why she put so much effort into her resettlement case. She retrospectively argued: "This stick is what made me be accepted [for resettlement], but they had first also refused, because I came after them [other refugees]. I made a strong follow up until I got it … I do not know how life in America is. For me, in my mind, I think when I reach America, maybe they will treat me and I will be fine like the others are".

∴

Martin and Bernadette's stories charted changes to their bodies over time. These changes had come along with diminishing abilities to carry out certain tasks like reading or farming, or with increasing pain. Both experienced these changes as loss, of not being able to do what they used to, and they felt remorse about this situation. Their stories, however, also pointed to the possibility of recovering certain abilities. Bernadette and Martin had a lot of hope that the right treatment and medication might make them 'normal' again. In this regard, their refugee status and the possibilities it offered seemed to take on additional significance because of their disability. Martin had only turned to the UNHCR for its protection and service provision after he became disabled, although he already had refugee status before then.

This chapter sets out from the starting point that the disabled body can be both a challenge and an opportunity for someone living in a refugee settlement. It thus examines in which ways disability is practiced and experienced as a category of difference, that is, in opposition to concepts of normalcy. The way in which disability figures as a category between difference and normalcy is decisive for how core problems around disability are understood, and subsequently approached by service providers. The service providers' approaches in Kyangwali were not clear-cut in this regard. As outlined in this book's introduction, both the medical and social models of disability played a role in Kyangwali. While disability was actually handled from quite a medical viewpoint in how it was defined, assessed, claimed and evidenced, a rights-based approach that promoted the social model of disability was gaining more and more importance. In this chapter I will look at the consequences that both these approaches were bringing about for my interlocutors.

First, I will explore the UNHCR's official definition of disability. As a category within the PSN framework, disability was mainly understood from a medical standpoint. The importance of medical standards also came to the fore in how disability was assessed in Kyangwali. Who counted as disabled or not was, however, not a clear-cut issue. I demonstrate this by showing how the aid agencies' available resources and a politics of numbers also shaped categorical definitions.

The second section of this chapter looks at disability as a category of difference from the perspective of people with disabilities. In their claims for support, but also in their experiences of acquiring a disability at a certain point in their lives, people with disabilities often dissociated themselves from *watu wazima*, an expression which literally means 'whole people'. I will take into account how my interlocutors made claims via bodily difference, and show how the need for medical proof often led to disappointment when service delivery did not fit medical requirements that resulted from medical examinations. The section also considers in which ways bodily difference was entangled with personhood. Taking into account Livingston's concept of "building"

(2005, 15), my observations suggest that bodily difference was more important for accessing aid than for constituting people's personhood. Being a person in Kyangwali's society was defined socially, rather than through values of individual, bodily abilities (see also Devlieger 2023, 7; Ingstad and Whyte 1995, 11).

Yet, disability held a particular place in the institutional and economic setting of the refugee settlement, precisely because it could enable access to resources, which were important for 'building' projects and relationships with others. The third section of this chapter focuses on the promotion of a rights-based approach and the social model of disability, investigating the critical consequences this had for disabled people's attainment of personhood through 'building' relationships and opportunities in the refugee settlement. I argue that the turn towards this approach only created limited opportunities for equality, and instead produced the risk of perpetuating the unequal relations between service providers and people with disabilities.

3 The Definition of Disability as a Boundary Device

Ever since my first visit to Kyangwali I had tried to obtain the official number of people with disabilities in the refugee settlement, and this became a never-ending exercise. When I inquired at one aid agency's office for any kind of statistics, they referred me to the next one, whose employees sent me further on or back again. Aid workers informed me that their numbers were not up to date, or explained that the numbers from the last assessments had not yet been compiled. My emails to the higher managers within the aid agencies were unanswered or deferred via friendly replies. I was taken aback that I could not get hold of this data, as I knew that people with disabilities were registered as such in a central database as soon as they arrived at the Ugandan border's transit centres or the refugee settlement[2] and that, for instance, AHM's community social workers kept lists of all the 'vulnerable' people in their villages.

When I gradually gained access to the numbers, they diverged immensely. According to a January 2014 joint assessment from the UNHCR, the AHM and the NRR, 124 people with disabilities lived in Kyangwali.[3] A first 'rapid assessment' by Aid Global in Kyangwali in early 2014 listed 574,[4] while their promotional

---

[2] Some problems in retrieving numbers from the database certainly occurred during the transition period when the OPM started to use their own database, RIMS, in early 2015.

[3] Oral information from an AHM aid worker in April 2014.

[4] Oral information from an Aid Global aid worker in April 2014.

video mentioned that 1,872 people with disabilities lived in Kyangwali.[5] A UNHCR source listed a total of 407 people with disabilities in Kyangwali refugee settlement in 2015,[6] while an article on Aid Global's website spoke about 5,000 people with disabilities.[7] What exactly was happening here?

The definition of disability, as Stone (1986) argues in her work on the welfare state, marks the boundary between the 'normal' state of accessing resources through work, and the special status of receiving social assistance. As the category works as a boundary device, its definition is of utmost importance: in comparison to other categories that entitle people to social assistance, such as old age or widowhood, it is much more difficult to determine eligibility for support based on someone's ability to work through their bodily state (see also Kelly 2017, 110). Stone argues that it was because of a need to use the most objective criteria possible that medical diagnosis and certification became so crucial for the definition of disability (Stone 1986, 3).

A comparative study by legal scholars examined the UNHCR's categorizations for identifying disability in displaced populations in different countries, including Uganda (Smith-Khan et al. 2014). These scholars argue that, although the UNHCR has acknowledged a shift away from the medicalized labelling approach towards recognizing environmental factors alongside impairments as the determinants of a person's disability – as proposed in the UNCRPD – the categories' criteria and their application do not reflect this sufficiently (17). In the UNHCR's booklet *Guidance on the Use of Standardized Specific Needs Codes* disability is described as "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".[8] The sub-category "physical disability" is differentiated into either moderate or severe:

> Physical disability – moderate (DS-PM): Person who has a physical disability from birth or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently. This category may include mine victims and persons who lost fingers or limbs, which may be corrected with a prosthetic device.

---

[5] Aid Global, promotional video, 2015.

[6] UNHCR, PSN statistics, received by email in February 2016 from a UNHCR aid worker.

[7] Aid Global, online news article on 'Inclusive WASH' project in Kyangwali, April 2015.

[8] *Guidance for the Use of Standardized Specific Needs Codes*, document received from a UNHCR representative in July 2015, page 5.

> Physical disability – severe (DS-PS): Person who has a physical disability from birth or resulting from illness, injury, trauma or old age, which severely restricts movement, significantly limits the ability to function independently or pursue an occupation, and/or requires assistance from a caregiver.[9]

As Smith-Khan et al. (2014) observed, this definition clearly starts from the bodily impairment as the cause of the disability, assuming that it is this dysfunction of the body that needs to be addressed in order for a person to "function independently". Rather than viewing it as a result of the interaction between bodily, social and environmental factors, this definition of disability locates inability within the individual body, that "may be corrected". The idea of "functioning independently" in this UNHCR definition is the criteria which is used to objectively measure disability. The definition of disability within the *Guidance for the Use of Standardized Specific Needs Codes* includes the following note: "Assessments of the patient to define whether the condition is moderate or severe would require a specialist/qualified personnel".[10] No clearer definition of "specialist/qualified personnel" is provided, but aid workers with whom I discussed this definitional requirement confirmed that this included medically-trained staff.

This was evident in how PSN assessments were made. I once observed a 'Vulnerability Assessment and Verification' exercise in Kyangwali. On the veranda of one of the aid agencies' offices, aid workers had to use a 'Vulnerability Assessment Tool' to decide whether a person counted as a 'person with specific needs' or not and, if so, which sub-category they belonged to. Applicants approached the tables with their documents ready: as well as their attestation cards they carried reports from doctors and Uganda's Ministry of Health, or exercise books with written diagnoses from local health centres. If people could not show the necessary medical attestations for the problem they claimed to have, they were refused the right to be considered in the PSN category, or were sent away with the instruction to see a doctor who would determine their grade of impairment. Thus, even though the UNHCR acknowledged the UNCRPD's definition of disability, its defining criteria and practice of assessing disability clearly pointed to a primarily medical understanding of it.

For the aid agencies in Kyangwali who aimed to distribute scarce resources in a fair and systematic way, this medical definition of disability as a boundary device upon which decisions for deservingness were made played a crucial

---

[9] *Guidance for the Use of Standardized Specific Needs Codes*, 5.

[10] *Guidance for the Use of Standardized Specific Needs Codes*, 5.

role. However, my encounters with the wide variety of numbers described above also indicated the further processes at play in shaping the definition of the disability category. When I queried the diverging numbers I had come across in Kyangwali with an aid worker, he explained: “When Aid Global was here and gave support to people with disabilities, the elderly were counted as people with disabilities. The resources were there”. The comparably vast amount of funds that Aid Global had available to implement their project had allowed them to broaden their definition of disability to include a high number of elderly and other fragile or debilitated people within it. Yet, it was not just the resources already available that contributed to shaping definitions, as aid agencies also relied on a large number of beneficiaries in order to justify and receive further funds for their projects within the competitive aid environment.

The organization measured its project’s success by counting the number of people that took part in their workshops or needs assessments, as well as those that benefitted from the accessible infrastructure and assistive devices it provided (see Chapter 3). The fact that aid agencies can report a large number of beneficiaries proves the relevance of their projects and facilitates access to financial resources (see also Swidler 2009, 204). Just as Smith (2004) proposes that ‘having people’ as dependents within patron-client relations enables access to opportunities and resources, ‘having people’ with disabilities in a refugee settlement seemed to become especially rewarding for allowing aid agencies to obtain funding to implement their projects, due to the assumed ‘double vulnerability’ of these beneficiaries.

The UNHCR decided which aid organization it would fund to undertake certain domains of their protection mandate. The various NGOs that were appointed to deliver medical services, community services or food provision in the refugee settlements counted as the UNHCR’s implementing partners. At the time of my fieldwork, Aid Global had not yet obtained any funding from the UNHCR to implement their projects, so were aiming to become an implementing partner in the future. Their expertise on the topic of disability meant that they were very likely to achieve this aim, since the UNHCR was not well versed in the topic, and pressure to give disability more attention was growing rapidly, through both research and advocacy on disability in the humanitarian context.

This shows how institutions adopt diverging definitions of disability according to their respective remits and missions (see also Ginsburg and Rapp 2013). The definition of disability as a boundary device thus has a different function, depending on the situation for which numbers are required. For organizations in the settlement that were delivering aid to disabled people on a regular basis, such as food rations or hut construction, their definition of disability had to match the UNHCR's longer-term budget plans, so often took on a more restrictive form based on medical criteria. For organizations that had sufficient funding, and depending on what position they wanted to achieve within the aid environment, definitions could be more open, to include the highest possible number of beneficiaries in order to both account for the project's success and emphasize the need for intervention – and thus the need for new projects. The next section discusses how disability as a category of difference was relevant for my interlocutors in terms of both claim-making and personhood.

4 Disabled, Not Whole: On Claim-Making and Personhood

One day when I was talking to Daniel, who was unable to walk and in great pain since a motorcycle accident, he recounted how he had gone to the agencies' offices and asked to be added to the list of EVIs: "I said 'you can't chase me [away from the office], I am disabled, and not whole'". Daniel spoke very fast when he told me this story, but articulated his words very clearly when he said, "I am disabled, and not whole". A disabled person asserting themselves to be "not whole" in the camp could mean many things. The term *watu wazima* was used to refer to 'normal' or 'able-bodied' people, and my research assistants mostly translated it as such. Yet, the term was also used to mean 'adults'. Hence, people were not only using it with regard to their bodily capacities, but the equation of *watu wazima* with adults suggested it was also about responsibilities, roles, and social capacities. Starting from these different distinctions of 'being whole', I will explore bodily difference in relation to both claim-making and personhood.

In Chapter 3 I described 'comparative benefits' – how people with disabilities perceived themselves as being entitled to claim benefits through comparisons with others. They contrasted their own circumstances with what they saw other disabled people receiving, but they also made comparisons with able-bodied people in their claims of being dependent, unable and in need of support. Given the status of a 'double vulnerability', it was not surprising that disabled people particularly claimed entitlements via bodily comparisons. This section focuses on claim-making via the body in terms of proof, to ascertain the consequences the medical model of disability had for my interlocutors in this regard.

Since a disabled body could provide opportunities to access resources and services, problems of proof and deception became critical. Stone argues that "the link between the formation of disability as an administrative category and its definition as a medical phenomenon is the concept of deception" (1986, 28). In order to make use of the opportunities arising from disability, my interlocutors were confronted with the constant need to claim their deviance (see Mirza 2011a), whether by showing parts of their body or through medical documentation. Every time I visited Martin I was reminded of the immense importance that medical documents had for refugees with disabilities. To substantiate his assertions, Martin often said: "I have the paper!'" He always carried some sort of bag to keep his papers within reach, such as a belt bag with his latest CT scans, or his briefcase filled with letters of referral from Mulago Hospital.

Martin relied on these medical examinations and documents to be recognized as in need of support. Based on medical assessments, doctors made recommendations for his specific treatments such as medication and food. While these recommendations increased Martin's expectations and hopes, they turned out to be rather empty bureaucratic procedures for him. His medical reports advised him to stick to a special diet, but the food he received in the Medical House and from the aid organizations in Kyangwali did not support this requirement. Similarly, Bernadette was frequently unable to access the treatment she needed at Kyangwali's NGO-led health centres, so she tried to acquire it more cheaply through intermediaries in Congo. Thus, whereas my interlocutors relied on medical proof to acquire their disability status, the situation of service delivery in Kyangwali often did not fit with the medical requirements that had been revealed through medical examinations.

People with disabilities also experienced such paradoxical outcomes in regard to assistive devices. The framing of disability as a bodily incapacity put the provision of assistive devices centre stage in the aid agencies' approach towards disability. In my encounters with most aid workers, the need to give disabled people assistive devices was one of the very first things they brought up in conversations. Even though the provision of assistive devices was one of the aid organizations' priorities, my interlocutors often had to wait for very long periods of time to access them, or to have them repaired. Claire (case 7) explained the aid agencies' disregard for the importance of assistive devices in disabled people's lives by saying:

> You find for sure we, the disabled here in Kyangwali, we have no value at all. I can give myself as an example: when this crutch is spoilt, you cannot reach community service. And then they tell you "wait, wait, we shall first have to hold a meeting with the UNHCR, that is when you will get a crutch". I don't know whether they know that this is the leg of a disabled person.

Assessments for people with disabilities' needs for assistive devices took place twice a year in Kyangwali. For this purpose, an orthopaedic doctor would spend one day in the settlement and decide which device best fit which body. The longest waiting time was for the expensive made-to-measure tricycles, as budgets always had to be confirmed by a higher authority, and because the bureaucratic procedures were so complex.

The somewhat paradoxical outcomes between the need for proof and what was eventually provided became especially obvious in the case of resettlement. Martin showed me a letter from a doctor recommending that he should be medically treated abroad several times. This stated that the medicine available in Uganda was not ideal, and advised medical treatment in a European country. Martin placed a lot of hope on being resettled in a third country, as he expected that better treatment would help him regain his former strength and abilities. Martin constantly discussed his chances of resettlement due to medical reasons with different aid workers. He told me: "They promised me, and said to keep waiting. They said, 'you be patient'. I am patient! But to be patient, I need to have the medicine!" The possibility of resettlement made disabled people invest in acquiring the necessary documents and proof of their need for further treatment abroad. As in Bernadette's case, sometimes people were actually successful (see Chapter 7).

Yet, although the medicalization of disability in assessments and verifications emphasized people's need in medical terms, the service delivery was often not forthcoming as recommended by doctors and thus expected by my interlocutors. Disabled people claimed their bodily difference along this medical understanding, so were disappointed when the aid agencies did not support them enough with medical treatment and assistive devices to make their bodies 'whole'.

The ways that the expression *watu wazima* was juxtaposed in opposition to disability implied that disability denoted an idea of loss or lack. Coming back to *watu wazima* as an expression for adults, and considering a common perception that children are not yet 'whole people', disability seemed to be viewed as a state of personhood that signified some deficit (see also Zoanni 2018).[11] It is interesting to note that other Swahili words describing people

---

[11] Referring to concepts of African personhood that were discussed by Meyer Fortes among the Tallensi people in Ghana, Tyler Zoanni takes up descriptions of children and mentally disabled people as having 'marginal personhood', as they lack *yam* (thought, judgement, sense of reality, reason) (2018, 309). Zoanni starts from the proposition that, while children usually overcome the marginality of their personhood when growing up, mentally disabled people might permanently not acquire full personhood in the sense of *yam* (2018, 64).

with specific disabilities are found in the noun class of 'ki-vi' (*kilema/vilema* for paralyzed people, *kipofu/vipofu* for blind people and *kiziwi/viziwi* for deaf people), a class that signifies objects rather than people. By setting disability in opposition to 'being whole', people clearly saw themselves, and were seen as, different, not 'normal'. However, a lack in bodily functions or appearance does not necessarily diminish personhood in a context where it is primarily defined in terms of being a member of a family and having children (Ingstad and Whyte 1995, 11).

Disability's history in the Western world has met concepts of normalcy in stigmatizing practices like 'freak shows', eugenics or spatial segregation, but also in activist endeavours to rights that enable 'normal' lives (Livingston 2005, 10). Livingston cautions against taking such a conception of normalcy in conjunction with disability for granted, although this Western conceptual history has increasingly influenced imaginations and practices of disability in other parts of the world (10). She writes:

> I think all societies, be they "western" or "eastern" or "southern", have a concept of the physically and mentally normal and a normative view of themselves (and their past) which people draw on to understand bodily difference. But in many societies where health and physicality are located and defined within social (particularly kin-based) relationships, notions of "normal" bodies and "normal" relationships are two sides of the same coin.
>
> 2005, 10

It is important to consider how my interlocutors perceived themselves and their disabled bodies as being positioned within social relations and in regard to other bodies. When I talked to Patrick, he asserted: "The way of our life here in the camp, we have no way to support ourselves like able-bodied people". Claire (case 7) expressed worries about her relationship with her husband when she said: "He is also a human being, tomorrow he will get tired and throw me there! But they are just giving help to people who are normal. Those things annoy me very much".[12] The crux of these bodily comparisons seemed to be the way that being able to support yourself and your family was viewed as a crucial aspect of attaining personhood. Consider Claire's statement about livelihood support for 'vulnerable' people: "The goats were given to women who are strong. The woman has a disabled child, but two hands and two legs and she is well – this is the one who received a goat. We, the disabled people in

---

[12] It depended on the translator what word they used for *watu wazima*. In the first case the word was translated as 'able-bodied', in the second case as 'normal'.

Kyangwali, did not get the goats. Why are they not supporting us so that our children can also have things meant for the disabled?"

Claire was referring to a livelihood programme that only targeted households with children who had been categorized as disabled, as required by its donors. The statements highlight that what mattered for Claire was her ability to fulfil her role as a mother and a wife. Claire had concluded the following from these kind of situations:

> Those *wakubwa* [Swahili for 'leaders'] do not differentiate between the people with strength and ability and those who are weak and disabled. They say all the 'vulnerables' are entitled to help and support. Most times in the meetings they tell us that these people may be suffering from chest problems, asthma or other diseases, which make them fall under the 'vulnerables'. Yet when you see them, you will realize that they are very normal. They even walk upright normally. What surprises us is that these are the people who receive the best of the distribution.

Claire seemed to define normalcy in certain bodily terms which were linked to appearance and visibility. Meanwhile, she understood the notion of personhood less in physical terms, but in social terms of successfully providing for a family or being a responsible adult. Therefore, despite this bodily association between disability and normalcy, being without a 'whole body' did not necessarily mean a lack in personhood, given that one is able to 'build' families. 'Building' suggests a concept of personhood that is processual and relational, "more than it does a sense of idealized body types or capacities" (Livingston 2005, 10; see also Ingstad and Whyte 1995, 11). Tyler Zoanni characterizes this state of personhood as "forward going" or "becoming", something that an individual gradually attains during their life (Zoanni 2018, 67; see also Comaroff and Comaroff 2001, 271).

In this sense, some of my interlocutors experienced not having a 'whole body' as a difficult situation. Like Martin and Bernadette, those who had acquired their disability at a later stage in life often compared their current situation of going about daily tasks remorsefully against the bodily capacities and energy they used to have. They seemed to experience a rupture in their processes of continually becoming 'whole people'. Claire shared her thoughts on this: "I always say, maybe at least if I was born like this, maybe I would not have any thoughts. But things came when I was normal, when I had produced three children, that is when the accident came like this".

Considering these and other comparisons people made with 'whole people', bodily difference presented a challenge for their personhood, because they faced difficulties in 'building' families and other projects. However, personhood was ultimately defined socially as well, rather than solely in physical terms. A lack or a loss in bodily functions or a change in appearance did not necessarily result in a loss of personhood, but it seemed much more of an issue if an individual's circumstances meant that they could continue the process of becoming a 'whole person' or not. As a categorical status, disability in a refugee settlement potentially enabled people to access the resources needed for this process. However, the expanding relevance of the rights-based approach in the humanitarian world ran the risk of diminishing this potential, as the next section discusses.

5 Contested Recognition in a Rights-Based Approach

When Bernadette referred to Aid Global as the organization that had "brought them together", she was speaking about "the disabled" as a group she belonged to. In many instances my interlocutors talked about their own experiences as an example of what other people with disabilities were also going through. "Us, people with disabilities are suffering a lot because of …", or "we, the disabled here in Kyangwali …" were sentences I frequently came across. These expressions could constitute a way of claiming recognition, both as a group and as individuals, they could express personal connections amongst each other, or they could possibly imply identification with a person's own body.

As outlined in this book's introduction, the social model approach to disability is closely entangled with a rights-based focus – both of which were particularly pronounced in Aid Global's project. In order to raise awareness and fight negative attitudes around disability, this organization had founded a drama group. One day I observed one of the drama group's rehearsals in a youth centre's green compound in Kyangwali. Vitali (case 5), the group's chairman, announced that the purpose of the meeting was to prepare for the upcoming visit of a donor delegation from Finland. Under the guidance of a community mobilizer, the group decided to perform some scenes depicting how much Aid Global supported them. In one of these, Claire (case 7) acted out a situation in which she was fetching water from a borehole by herself. However, some children disturbed her in the process, snatching her crutch and teasing her with it. Another scene showed parents hiding their disabled child when aid workers visited for an assessment. The child ran after the aid workers, but it took a while for the parents to stop denying their child was disabled. When the child enrolled in a special school for disabled pupils, the parents were happy, especially as they did not have to pay the school's fees. These and other scenes enacted by the drama group portrayed situations of discrimination and unequal access, calling for disabled people to be empowered.

Although Aid Global's one-year project in Kyangwali came to an end at the beginning of my fieldwork, it was often a topic of discussion in conversations with disabled people. Their contact with the project had only recently ended, and some activities were still ongoing, like the drama group's activities for donor visits and certain festivities. In order to reveal what was at the core of expressions such as 'us, the disabled', I explore how a rights-based approach to disability was implemented in Kyangwali, and examine some of its contested configurations.

Most of my interlocutors appreciated Aid Global's attention and support, and the fact that they had been recognized by an organization that specifically addressed disability. For instance, looking back at the project, Mugenzi said: "It was a good experience since before other people attended seminars and training, but people with disabilities would stay alone. But now we have started to join others and also attend training sessions". As well as the drama group, Aid Global had organized workshops in which they trained disabled people in matters of hygiene and sensitized them about their rights, but also asked them about their needs and what kind of support would help them most. Bernadette remembered being told in a meeting that disability was not a bad thing and that disabled people were capable and intelligent. Camille (case 6) explained in regard to the drama group: "It helps me, because of the things we act, they teach me and make me feel better". Remember that Camille had lost her arm in an incident where she was imprisoned with others in a hut which was set on fire by armed men. I once saw her act out a similar scene in one of the drama group rehearsals. Depending on people's attitudes towards their own disability, which often correlated with the time and circumstances they had acquired it, people seemed to find comfort and confidence through such activities.

Aid Global's training and workshops were also of varying significance depending on the position someone held within the project and the responsibilities and opportunities that came with that. Claire (case 7), for example, became a community facilitator: "When Aid Global reached here, they gave me the feeling of discovering that I was also as important as other people. They took me to a workshop for one week. They taught us how we can manage our lives with our children". Claire went on to recite what she had learnt about hygiene, for example, how to keep cooking utensils free from germs, how to store water, that it was important to use soap when washing hands after going to the toilet, and to advise her children about it. She also recounted that she was used as an example to show disabled as well as able-bodied people that people with disabilities are not incapable, but can do things for themselves and their families.

When Claire talked about her experiences with Aid Global, something else was also being foregrounded besides gaining knowledge and confidence, however. The relationships that evolved around the project and people's identification with it did not first and foremost emerge from shared experiences through bodily difference, as anthropologists have observed in other contexts, especially in relation to support groups formed around chronic diseases (Nguyen 2010; Rapp 1999; Rose and Novas 2008). The reasons why people chose to participate in such groups also differed from what Whyte and Muyinda (2007) observed among Ugandans with mobility disabilities who came together and formed an association out of their common interest in border trade. Whereas they had assembled on their own initiative, my interlocutors in Kyangwali gathered as a group of people with disabilities when meetings were initiated from the top down. When I asked one of the leaders of the disability association initiated by Aid Global about any planned meetings, he said: "We wanted to do it, but when we heard that Aid Global was leaving, the strength reduced". This was because, first of all, bringing people together in a satisfactory way required money. Secondly, if no one from the aid organizations or visitors were around to listen to their claims, such exercises seemed pointless. When I asked Claire about this, she said: "They [the meetings] will end completely because the supporters have gone. They were the ones supporting us with those things. We keep trying, however, when there is a certain 'big person' coming. That is when they call us and we prepare some little drama, but that is all".

This revealed that the meetings were not primarily used by disabled people to share their experiences, and did not noticeably shape new identities and socialities around them based on their bodily difference. When disabled people told me Aid Global was the organization that recognized them, I had first thought they meant that the organization was promoting their rights, or that they talked in support groups about what it meant to be disabled. I realized that, instead, participating in such events provided first and foremost opportunities for distributive labour and access to material benefits. As Chapter 5 discussed, it was less the content of Aid Global's meetings, but rather their format and organization that made my interlocutors feel recognized. Claire compared Aid Global's meetings to what she had experienced from other organizations: "When AHM used to call us for meetings, in those meetings we would spend the whole day without even drinking water given to us. But in Aid Global's meetings – why we say it pleased us so much – we would take a tea break and we would also eat and everything would be good".

Certain such events were, however, despised by other interlocutors. Mugenzi, the man who had both legs amputated, complained about the activities on World Refugee Day, an annual celebration that included representatives from donors, government and international NGOs, where groups of refugees made some sort of presentation to the service providers. During the 2014 World Refugee Day, disabled people had given a speech in which they made their claims known as a group by invoking their rights as refugees with disabilities. Mugenzi felt that such efforts were useless, and that the aid organizations should support him with his children's education instead, as he lacked the resources to do so. Another of my interlocutors told me: "I have attended a meeting concerning the construction of houses for us, but even after this meeting, nothing has been built. We go there to explain our needs to them [the service providers], but they do not help".

Ferguson cautions us that neoliberal "rights talk" does not really contain claims to a "rightful share" of the resources held by states and other institutions (2015, 48). As he notes for poor people in South Africa, people with disabilities in Kyangwali did not stake distributive claims in reference to equality and rights (49). They understood their entitlement and the validity of their claims based on their hierarchical relationship to the aid agencies and their position as eligible dependents within that, as well as according to the distributive labour they continuously invested into those relations. Yet, while disabled people's complaints could certainly be understood as claims towards more equality, the aid agencies seemed to dismiss these as high demands located in the 'dependency syndrome'. Aid Global's brochure remarked on the limitations of their project, stating that it "could not meet the high expectations on the side of the beneficiaries".[13] This is precisely one of the dangers of a rights-based approach – the risk that it might undermine any chance of redistributing wealth and resources. Rather than merely being officially acknowledged as an equal rights-holder, it is the recognition of demands such as being supported with children's school fees or with a house that would make a genuine difference to the disabled refugees' lives (see also Ferguson 2015, 48).[14]

The approach of sensitizing people about their rights was in line with current development trends and disability discourses, and thus served as a form of proof that people with disabilities were being cared for accordingly by the aid agency. In this way, Aid Global positioned itself as a role model taking a progressive way forward that focused on disabled people's equality and independence. The recognition of disabled refugees within this framework of universal rights thus featured as a marker of progress and modernity, which sometimes seemed to be more relevant and useful for the aid organizations

---

[13] Aid Global, project brochure, 2015.

[14] I discussed in Chapter 5 how direct material and financial assistance made a difference to my interlocutors' lives.

than for people with disabilities themselves (see also Hartblay 2017). In their discussion with the UNHCR about becoming an implementing partner, Aid Global submitted a project proposal that specifically focused on advocating for disabled people's rights, and it was precisely its rights-based approach to disabled people that made Aid Global a competitive candidate in the struggle for the UN organization's resources.

The project which Aid Global proposed to the UNHCR in April 2016 was to be implemented in another of Uganda's refugee settlements with a budget of 2,000,000 US dollars for five years, and aimed to improve "the well-being of people with disabilities through equity and inclusion interventions".[15] As well as improving access to WASH services (as described in Chapter 4), the proposed activities included community awareness workshops, quarterly advocacy meetings, an annual conference on equality and inclusion, media campaigns, policy briefs, and the formation of drama groups. The only aspect that covered direct assistance in the form of inclusive boreholes and toilets comprised around 10 percent of the total budget.[16] This revealed a major discrepancy. Whereas promoting the rights-based approach made funds flow for the aid agency, the outputs for disabled people were sensitization training and rights advocacy. Claire (case 7) told me about one of Aid Global's workshops, in which disabled people were told "if you are disabled and you have wisdom in your eyes, you can do work and your child can get soap and food". This shows how the aid agencies seemed to think it was more important to teach people to become empowered than to give them tangible items to directly benefit their everyday lives. This experience, whereby people with disabilities were recognized within the framework of universal rights, but in the end hardly benefitted in a manner that would have made them more equal in any way, is what I call 'disappointed recognition'.

6 Contested Relations through a Rights-Based Approach

Martin (case 9) and Jacob (case 4) were the only people with disabilities I met in Kyangwali who explicitly referred to rights in their claims for support and protection. They were clearly an exception in this regard. Martin's

---

[15] Aid Global, project proposal UNHCR, received by an Aid Global aid worker in April 2016, p. 1.

[16] Aid Global, project proposal UNHCR, p. 8.

personal background of involvement in the human rights movement in Congo enabled him to draw on his knowledge of rights advocacy in his claims for better support. His evocation of rights seemed to be particularly powerful as he was well-known to be in touch with various rights organizations, such as the Refugee Law Project in Kampala. Yet, in his case, I would argue that it was his relationship with high-profile aid organization officers that also played a role in making things work out for him. Through his proximity to the offices and his eloquent nature, he was often in contact with aid workers and listened to by people who had decision-making power. Through his negotiation skills, he managed to obtain special reading glasses, electricity to power his room, and organized medical referrals to Kampala.

In her discussion of 'biological citizenship' after Chernobyl, Petryna (2013) describes precisely this – the fact that people negotiate benefits and entitlement not just based on their physical condition, but also on the basis of their personal relationships. I also noticed that in other cases it was a personal relationship with someone in a higher position within the aid system – be it a high-profile foreign officer, a Ugandan aid worker, or a community social worker – who eventually made things happen and facilitated help to be forthcoming. Such often hierarchical relationships, which disabled people invested a lot of effort into, were at times very relevant in addition to their medical diagnoses, having a certain categorical status, or being a formal 'rights-holder'.

For example, this played a role at the Word Refugee Day event alluded to above. The speech in which disabled people made their claims known was given by a young boy and was explicitly addressed to the guest of honour and the UNHCR Uganda country representative. The speech seemed to have an impressive impact on the high-profile visitors. They posed for pictures with the group, photographed by the media people, or with their smartphones. Eventually, the guest of honour announced that she would donate a bicycle to the young boy who had given the speech. He had difficulties walking due to a debilitated limb, and the bicycle would considerably ease his everyday journey to the secondary school he attended. What I found particularly interesting about this example was that the 'rights talk' raised in his speech was somewhat at odds with the ways assistance was subsequently provided, in an act that was rather reminiscent of a hierarchical relation to a patron and a charitable act, instead of being based in ideas of equality.

Disabled people's positioning as beneficiaries often played out in less beneficial ways than was the case for this young boy or Martin, however. My interlocutors put particular hope in their relations with *wazungu*, or white people, who were associated with wealth and decision-making power. For Vitali (case 5), though, his relationships with people from Aid Global did not turn out as expected:

> We acted several times [with the drama group] and pictures were taken, we attended their seminars. But at the end, we did not get anything out of it. People from Finland came, one man and two ladies. They saw our drama performances and left. Another time, two other ladies came with two gentlemen, one of the gentlemen knew Swahili. Those ladies interviewed me and asked me what I would like to be helped with. I told them that if they were to send their help to me here in the camp, I wouldn't get it. That if they were to help me, let them take me to Europe with my sons … They recorded everything and took my pictures. Later on, two other white men came, they took me to the water tap and interviewed me about how I fetch water and they brought me a gift from Finland in this envelope. They told me to keep those papers. I don't know whether they [the papers] will take us to Europe.

We were in Vitali's hut, where he pulled a brown envelope out of a pile of papers beside his mattress and took out a newspaper article in Finnish and some photographs of himself. It did not seem to me that those papers would have any influence on his and his nephews' chances of being resettled in a European country. When I asked how he felt about this situation, he replied:

> I don't look at it in a bad way, when a person asks about my problems and takes pictures. I don't feel bad at all. Whether they go to sell those pictures, I don't know. Let me tell you, these people from Finland took many pictures. But still now I don't know what was the meaning of it all, whether the support will come. If a person wants to know [about me] I can't refuse him or her. They interview me.

Vitali told me all this while I was interviewing him. I felt uncomfortable in the situation but, over the course of my fieldwork, I gradually learnt how to deal with the ways in which I was also becoming part of people's distributive labour (see Schuler 2018). When Vitali rehearsed and performed for donor delegations in the drama group, when he had his picture taken, or when he was interviewed about his needs, he was certainly hoping for a share of the aid agency's resources. This should not be altogether surprising, as Vitali featured prominently in both Aid Global's brochure and their promotional video, which seemed to have had a positive impact on the organization's future prospects.

Vitali's vision of a good life was outside the refugee settlement, where his nephews could gain a good education and find jobs. Even though Aid Global could not fulfil his wishes, the organization's connection to Finland and other European countries kept his hopes up.

Such international relations turned out to be more advantageous in other cases. It was common for people who had resettled in the US from Kyangwali to send money to people they had left behind, even if they were not family. When Claire and her family reached New York through the resettlement programme, they sent six disabled people in Kyangwali, including Martin and Vitali, 10,000 Ugandan shillings[17] as a Christmas present. Through Aid Global's activities, my interlocutors had developed friendships with each other. I mentioned earlier how, when I was with Camille and Claire in Bernadette's hut during the heavy rain on a market day, Bernadette had told me that disabled people knew each other from Aid Global's activities. I had grown to know Camille when she was served *mboga* at Claire's place before one of the disability association's drama group's rehearsals which they both were participating in. It became customary for Camille to drop into Claire's place for a cup of porridge or the like when she was in the settlement's centre. Vitali also visited other disabled people, for example to show them photographs from the drama group's rehearsal. Some of these relationships became rewarding for my interlocutors. Refugees who were lucky enough to reach the US or another European country seemed to act upon a moral obligation to share some part of their new wealth with the ones left behind, even if it was a rather symbolic amount of money.

Whyte (2020) looked at disability programmes in a rural area of Eastern Uganda which only briefly touched disabled people's lives, and observed that disabled people's sporadic positioning as beneficiaries contrasts significantly with the durable interactions people have with their families and neighbours. This also held true for people in Kyangwali, but it is important to consider that they had often lost family members, so were more reliant on alternative support, while the aid agencies provided crucial possibilities of assistance on a regular basis. Although people with disabilities frequently did not receive what they had hoped for from Aid Global and other organizations, they kept trying. This signifies "hopes for durability" (2020, 136), as Whyte describes the situation when people orient themselves towards projects "in a subjunctive mode of hope and doubt" (135).

My interlocutors kept on hoping for a longer-lasting relationship with Aid Global even after the project had ended. Claire explained: "They [Aid Global]

---

[17] Approximately 2.5 US dollars.

told us that they are going because they were allowed to work in every camp for one year. They came here for a year, it is Adjumani where they are going now". When Amani inquired whether they would come back, Claire answered: "We don't know, we are waiting, because they said when they start work properly in Adjumani, they will call us to go and teach those in Adjumani". During my fieldwork period, disabled people were never called to engage in Adjumani, but in December 2015 they were invited to perform their drama in Tororo district in Eastern Uganda, to celebrate the International Day of Persons with Disabilities. What was important in all this, though, was the fact that it was the aid organizations setting the pace and conditions of any future interactions. The event in Tororo provided a good opportunity for Aid Global to represent their beneficiaries' empowerment and participation – one that might be questionable, however, as has been shown in this section.

7 Conclusion

This chapter has explored how people with disabilities in Kyangwali were approached through both medical and social models of disability. In different situations, such as during assessments for PSN status or assistive devices, in workshops, or during World Refugee Day celebrations, various concepts of disability were put forward by different organizations, with diverse and far-reaching consequences for disabled people.

The UNHCR's written definition of disability is anchored in an idea of bodily functioning and independence, and this predominantly medical understanding also played a role when disability was being assessed practically. This chapter has revealed, however, that aid organizations' funding and programmes also shaped the definition of disability, when it was viewed as a boundary-setting device. Just as a disabled body could provide opportunities, disability was closely bound to the concept of deception, which required people to render their disabilities visible, often accompanied by medical proof. These processes and procedures emphasized need in medical terms, but the responses to this need were frequently not forthcoming as expected.

By exploring what it meant for disabled people in the refugee camp to become 'whole' as people, this chapter has demonstrated that what constituted personhood was defined less in bodily terms, but rather in the social terms of successfully providing for a family and being a responsible adult. This led to the question of how the aid agencies' approaches supported disabled people in their efforts to attain personhood. This chapter has argued that the shift towards a rights-based approach ran the risk of increasing the unequal relations between disabled people and service providers, despite their advocacy for more equality and independence. This revealed the paradox that aid organizations gained access to resources by promoting a rights-based approach, but then, did not in fact redistribute these resources to disabled people in Kyangwali, when they used this very same approach in the name of advocacy and sensitization. Once more, people with disabilities were recognized as people that need to be empowered. Whereas they played their part, be it as participants in a workshop or drama group or as an interviewee, they usually did not receive the share of the donors' resources they had hoped for. This also emphasized the hierarchical relations through which the provision of aid worked – not only in regard to acquiring funds, but also in terms of relationships with certain aid workers who could channel access to resources and support as well as just abstract rights or medical diagnoses.

Anthropologists who have considered the role of the body within humanitarianism in other contexts warn of the depoliticization that often accompanies the medicalization of bodily statuses (Fassin 2001, 2012; Fassin and D'Halluin 2005; Malkki 1996; Ticktin 2011a, 2014). They assert that such processes are about a shift "towards a politics of the body as opposed to one of social justice or redistribution" (Ticktin 2014, 255). At first glance, the humanitarian turn towards a rights-based approach to disability appeared to be heading in the direction of social justice, as a result of the UNCRPD's increasing influence in this context. Yet, my fieldwork observed that the focus on rights as it was practiced in Kyangwali actually undermined redistribution, when it only allowed disabled people to claim their rights, and not any tangible items. This chapter cautions that, as long as the services based on rights are not improved, and as long as the aid organizations seem to profit more by 'having people' with disabilities than actually enabling people in their pursuit of personhood through 'building' families and projects, there is a need to continue critically questioning a rights-based approach in this context.

CHAPTER 7

When the Heart Does Not Settle – Life in Transit

1 Case 11: Anette

Abandoned land, a fall and wazungu

Amani and I arrived at Anette's home quite exhausted. Although we had made the journey on a *boda boda*, the steep, slippery roads had made the journey an arduous endeavour. Every time I went to the margins of the refugee camp, I was impressed anew by how far these places were to reach, even on bicycle, let alone on foot. Under a shelter in front of her house, Anette attended to a boiling pot of beans on the fire and a baby on her lap, the youngest of the five children she took care of with her husband. Their homestead occupied a cleared parcel of land not far from the roadside, and was accessed via a compound that was shared by four families. Anette's family had spent about two years living in Kyangwali after having fled the Eastern Congo region that was home to Beni, a town that had gained sad notoriety when several massacres of civilians took place there in 2012 and 2013. Like most of the people who lived in this part of Kyangwali, Anette and her family felt that they had only settled there temporarily. One immediately noticed the abandoned land which was being steadily reclaimed by bushy nature after its former residents had returned to their homes in Congo. It was thus not uncommon to see shared compounds like Anette's, because people felt increasingly insecure in this remote part of the settlement.

Anette spoke in hushed tones when we talked, as one of her legs was very painful because of a fall she had suffered the day before our visit. She had no money to pay a *boda boda* to take her to a health centre or to buy painkillers from a closer pharmacy. "The life that I have here in Kyangwali is a life of suffering," Anette uttered, before she paused and advised her teenage son to take the pot of beans off the fire. Like other people with disabilities I talked to in this remote part of the settlement, Anette asserted that aid workers did not regularly visit this area. She sensed that information often did not reach very far and suspected that people from this area therefore missed out on assistance. For example, she told me that the first time she came into contact with the organization Aid Global was when she was picked up in a van to attend their leaving event. Anette resumed: "That is the life I am going through here in Kyangwali, a life of suffering … Just a life of suffering. We need helpers to support us so that we can also have a good life". Many times Anette repeated the expression *maisha ya kutesa*, signifying "a life of suffering".

I had not known Anette for long, and she certainly hoped that I would be able to help her. This became even clearer during the course of the interview, when she said: "Sometimes I think of returning to Congo, because here I am suffering a lot. I don't have money for transport, but I am waiting for when the *wazungu* (Swahili for 'white people') will say we are taking you back, then I will go". I felt quite awkward in this role of a potential helper or patron, which Anette seemingly saw me as. Although I informed her over the course of our engagement that I did not work for any of the organizations and could not take any decisions regarding their stay, I obviously did not manage to convince her family about this, as became apparent in a conversation I had with them about a year later. Her husband stated:

> What we think is this: I think you are keeping us, and we are disabled, we are the ones that cannot help themselves. And those who take care, those ones are like you. You are the ones who look after the ones who cannot support themselves, the disabled … You always come to us here, every time you reach here, you are the one to help those who are disabled.

The day that we went there after Anette's fall, some neighbours visited or exchanged greetings from the roadside, inquiring about her well-being after the accident. It was not clear how badly her leg was affected, so Amani and I decided to search for a *boda boda* in the nearest village that would take her to a health centre. But there was no vehicle to be found anywhere, and there was no mobile phone signal. Instead we gave her some money for medicine and started to look for our own transport back home.

I had first met Anette when I visited Kyangwali in 2014. At that time she had not yet been reunited with her husband and some of her children, and expressed the wish to return to Congo. She had only lived in Kyangwali for few months then, and an aid worker who accompanied me had told me beforehand about her frequent requests to go back home. On that occasion we also discussed how she managed to cultivate her fields without her husband and other family members. Anette's disability was evident, as she walked stooped over and limping, stabilizing her right knee by pushing both of her hands against it while taking steps. I followed her to the fields where she planted maize and beans, while she explained that it was the first time she had ever farmed in her life, and that she used to plait hair in a small trading centre in Congo to earn a living. She had received some agricultural advice from the organization NRR, which also provided her with the first seeds, but her neighbours and relatives had also shown her when, where and how to plant and harvest. She teamed up with her children for the work: “Like, when a child makes the holes, I will drop in the maize like that … then the child covers the seeds, because for me I do not have the legs to cover the seeds”.

When I visited Anette again before travelling back to Europe, I barely recognized the place: there were more huts in the compound, which was surrounded by a field of maize. Her oldest son had built his own hut. Even though the place had started to look more like a permanent home, I sensed from their worn-out clothes and ramshackle dwellings that people still had fewer resources in this part of the settlement than in others, as they started to build their new lives as recently-arrived refugees. Chatting with some of her neighbours, Anette prepared beans for dinner. Other people dropped in, including their village chairman, who told me that Anette had been appointed vice chairperson in the last elections and was about to co-represent their village on the Refugee Welfare Council.

2 Case 12: Mugenzi

Knee pads, bars and poison

Mugenzi lived only a few blocks away from the Catholic guesthouse I was staying at, which is why I often had the opportunity to drop in and say hello to him and his family. The first time I talked to Mugenzi, he had said: “You will find me here. I am always seated here”. However, he was often out of the house when I visited, usually in one of the local bars nearby. One day I encountered Mugenzi’s daughter Maria sitting on a mat in the shadow of a banana tree with a heap of books and papers. She was studying for a diploma in accounting, which she was pursuing in Hoima, the nearest town outside the settlement, after completing secondary school. As was usually the case when her mother, father, younger brother or older married sister were around, I was offered yellow bananas from their field and fresh *obushera*, a sorghum porridge, which was very popular in the Ugandan-Congolese border region around Bunagana where they came from.

Due to the good marks she had earned in her last year of primary school, Maria had received a scholarship to study at Kyangwali Secondary School for four years. She stressed that, although her father would do everything he could to enable his children to access education, her further studies in Hoima were only possible due to the head teacher’s goodwill. He allowed her to study for free in exchange for doing work like cleaning the school and teacher’s apartments, as well as cooking for them. Stuck to the inside of Mugenzi's home there were posters and calendars from Coburwas Primary School where his youngest son was in school, and from Bugema University, a private university near Kampala where his second oldest daughter Miriam was studying. That daughter had a Congolese husband in Denmark who was paying for her tuition until she acquired the necessary travel documents to join him there. Maria told me that her father experienced a lot of envy from their neighbours, as his children were enjoying such a privileged education despite the fact that he was "like that", as she used to say when referring to her father's disability.

Another day when I visited the family, Mugenzi left their hut with his two wooden sticks and the kneepads that protected the stumps of his legs, which had both been amputated just beneath his knees. We sat down on the compound's wooden benches and chairs and Mugenzi placed the wooden sticks aside in such a way that he could stretch out the remains of his legs while we talked. I told Mugenzi that Amani had been sick for some weeks and that he suspected that unknown jealous individuals had poisoned him, at which point Mugenzi told me how his oldest two sons had died. It was a good thing that I had already heard some of this story from Maria before, as communication between us was challenging – as well as my struggles to master the language, Mugenzi's Swahili was also rather basic and his pronunciation mixed up with Kinyabwisha words.

He explained that, when they had arrived in Kyangwali, they were allocated a plot of land in another part of the settlement, and only later moved to their current location. Mugenzi recounted that they had moved because both his older sons were poisoned after finishing secondary school. They died shortly after each other, and Mugenzi strongly believed that the neighbours of their former plot had done this terrible deed. He paused our conversation to go into his house – the stump of one of his legs visible behind the knotted trouser leg that fell open – and returned holding a bible. In between its pages he kept documents and photographs, some of which showed scenes from his older son's wedding, another his coffin covered in a cloth at his funeral. Mugenzi told me that life had become challenging after his sons' deaths, especially as he could no longer afford the fees for his children who still attended school. Much of the agricultural work was now dependent on his wife, whose strength was also weakening because of her age.

As Mugenzi's former neighbours had continued to disturb them by stealing bananas and sugarcane from those distant fields, Mugenzi complained about them to the village chairman as well as the Office of the Prime Minister (OPM). This led to unforeseen consequences which gave the situation a critical turn, when the village chairman threatened to remove one of Mugenzi's family's two plots, which they were no longer officially entitled to following his sons' deaths. Mugenzi argued that this was his family's only livelihood, but eventually had to drop the case. Although Mugenzi's family could now still use more land than they were actually entitled to, Mugenzi often compared it to the land he had owned in Congo. He spoke enthusiastically about Bunagana's fertile soil for growing beans, sorghum, sweet potatoes, and especially Irish potatoes, delving into his memories of rearing animals. He said: "Here, I have nothing to sell. You cannot sell part of your land. If it was at home, I would have sold part of my land [to cover the children's school fees]".

Mugenzi did not know which disease had caused his legs to swell up so much that they had had to be amputated. While he was still living in Congo, he had crossed the border to seek better treatment at a hospital in Uganda. But he was not able to read what the doctors had written and had lost those papers when they eventually sought refuge in Uganda later on. Picking over the photographs from the bible, he pointed to one in which he was standing on healthy legs, happy to show me that he had been 'whole' back then. When a relative of his arrived at the compound, he was eager to take out the picture again to show it to her. Unlike this seemingly easy-going attitude towards his disability, he told me in an interview: "It was hard to see myself crawling when I was a man. I was like a kid starting to learn how to walk". When Mugenzi showed me more of the photographs, I learnt about a mentally disabled sister who had been resettled in the US, and that his mother had died in Kyangwali.

I was on my way for an after-work beer in one of the local bars when I glimpsed Mugenzi on his tricycle on the road in front of me. His company came just at the right time, as I recurrently experienced a flat tyre on my bicycle. Like many of the tricyclists I interacted with, Mugenzi knew well which roadside bike shop was better than the others, and how the men in the shop could best solve my problem. After he had also had his tricycle tyre pumped up, we parked our vehicles in front of a nearby house, and settled into the compound of a bar that was an annex to the owner's house. A group of people were already enjoying a discussion and, when Mugenzi's wife joined us shortly afterwards, the talk again turned to resettlement, like most of the times when people met during those days in April 2016. Many people were in the process of being resettled in the US, travelling to Hoima and Kampala for interviews and other evaluations, or selling and packing their belongings before catching their flights abroad.

As refugees who had arrived in Uganda in 1999, Mugenzi's family had already been given the necessary medical injections to travel, so were waiting to find out which hosting state they would be sent to. Mugenzi not only expected to have enough to eat and drink in an American life but, after being briefed by the International Organization for Migration (IOM) in a cultural orientation week, he told me:

> They are even telling me that I will get legs, and that will be helpful, because I have been here for long but I have not got such help from here … Even if I cannot find work, I can at least stand. I was shown people with disabilities [in videos on a computer during the orientation week] who were playing football and who can walk properly because they were given legs.

Despite the hopes Mugenzi had for resettlement, he also felt remorse that his youngest son had never seen their home country, since he was born in Kyangwali. Yet the older children who still were alive not only had memories of their home, but once in a while made visits across the border, as Mugenzi and his wife did one day when they attended a relative's burial. But Mugenzi stated: "We cannot count on Congo because there are bullets... I am no longer strong enough to run. Life is not all that good, but even though you may eat little, it is better than where people are being shot at in Congo."

⁂

Anette and Mugenzi's stories both convey a sense of the temporariness they felt about their stay in Kyangwali. Although they had lived in Kyangwali for different time spans and orientated themselves disparately towards their home country or a future outside the refugee camp, both understood their situation in Kyangwali as one in transit. Another of my interlocutors pointedly described this in a conversation: "Our heart does not settle. Sometimes they [the aid agencies] may take us by force and send us back to our country. We don't have a place where we can stay properly and where our heart settles so that we can forget the past".

Congo's refugee population was counted as the world's sixth largest in 2014, mainly consisting of people who had fled from the first and second Congo Wars of 1996–1997 and 1998–2003. The unstable security situation in many areas of Eastern Congo made it very difficult for most Congolese refugees to return to their homes. "Our heart does not settle" not only expressed the transitionary nature of life in a camp, but implied the longing for a more permanent home than a refugee settlement can provide. Simon Turner characterizes refugee camps as institutions that are "between the temporary and the permanent" (2016, 141). Refugees' lives in a camp can thus be understood as 'doubly paradoxical', as he writes: "first, they cannot settle where they are because they are supposedly ‘on the move’, on their way home or somewhere else in the future; second, they cannot remain ‘on the move’ as they possibly are not going anywhere, either now or in the near future” (141). Most of the people with disabilities I interacted with had lived in Kyangwali for between five and ten years, several for less than five years, but there were also many who had already lived in the refugee camp for over ten or even 15 years. This chapter examines people’s diverse orientations towards ‘home’, to investigate what this signifies for being a refugee with a disability. Being a refugee implies having lost a home, being given a temporary home, as well as searching for a home. How does disability play into these different dimensions of home?

Without assuming that the lives of people who have not fled their home countries are of a more permanent character per se, the notion of home seems to be a particularly multi-dimensional, transnational and dynamic process for refugees (Al-Ali and Koser 2003, 6). The question of home is not simply a matter of place, but also one of “a longing for a nostalgic past or a utopian future” (7). Although people had lived through troubling times in Congo, they often compared their lives in Kyangwali to a remembered better past. Yet they also imagined home as a better future in the US or a European country through the resettlement programme, despite the fact that this was only a viable option for a few of them (see also Boer 2015, 486). This chapter therefore considers the notion of home not only in regard to where people came from, but also concerning their current situation, and where they were going to.

What it means to be a refugee, what the changes and losses, the temporariness and future perspectives meant for people like Mugenzi and Anette cannot be easily assumed (see e.g. Eastmond 2007, 253). Anthropological research has substantially added to refugee studies by critically questioning the experience of forced displacement itself as the main aspect of what characterizes a shared sense of ‘refugeeness’, and emphasizing that common denominator in their lives is actually people’s experiences of humanitarian aid interventions (e.g. Harrell-Bond 1986; Malkki 1995). This chapter follows this strand of literature which describes people’s experiences of humanitarian aid as being very characteristic in their lives as refugees and in the ways they think about their pasts and imagine their futures. Just as Anette argued that the ones that are “keeping us” were supposed to “take care” of the camp’s inhabitants, people often reasoned that the aid agencies were responsible for their fate and well-being. What was distinctive for refugees with disabilities in this regard was that, despite all the challenges they faced, life in a refugee settlement also created possibilities that they would not otherwise have encountered. This chapter pursues this insight, to argue that the common experience that disabled people had through their displacement was shaped more by the humanitarian setting they found themselves in and their relation to the aid agencies than by shared feelings of cultural uprootedness, or their lost sense of belonging to a place or a community.

This chapter's structure represents the multi-dimensionality of the notion of 'home', since my argument is developed around disabled people's wish to return, their present situation in relation to memories of their past, and their imagined futures. The first section discusses the homes that people had left behind, reveals that they did not necessarily want to return there, and challenges a sedentary view of displacement. The second section considers "the life of suffering" in Kyangwali, contrasting it to the opportunities that were available for refugees with disabilities in the camp. In the third section I explore my interlocutors' aspirations, imaginations and possibilities for resettling in a third country. I argue that having refugee and disability status created important opportunities for making claims and accessing aid, which able-bodied residents did not have. This shows how disabled people's assumed 'double vulnerability' also signified a 'double opportunity' in regard to their search for a home outside the refugee camp.

3 The Home That Was

Reviewing the problematization of displacement and the approaches taken towards this phenomenon, it immediately becomes clear that they generally include an underlying assumption that people want to return to where they were displaced from. Other than people who migrate out of economic aspirations, refugees are approached from the viewpoint that they were forced to leave their homes. The solutions that the UNHCR targets perceive home as being defined through national boundaries, and eventually aspire to gain a prospective status of citizenship (Ramsay 2017, 13). This is evident in the three long-term solutions offered for protracted refugee situations:[1] repatriation back to the country of origin, local integration into a host country of asylum, and resettling refugees in a third country. The link between people and place, which is perceived in these national terms, is made explicit in the function of the UNHCR's community services, which assume that all human beings have an inherent desire to belong and contribute to a larger supportive community, and argue that this sense of belonging and community is always violated through displacement (Bakewell 2003, 6).

---

[1] The UNHCR defines these as situations where 25,000 or more refugees of the same nationality have been living in a country of asylum for at least five years (Krause 2016).

This assumption stems from a sedentary understanding of societies as being stable and local in one place, rather than dynamic and moving between places (Malkki 1995, 508). Such a perspective considers people as being collectively rooted in a given territory, thus viewing movement as inherently violent – a perspective that is common in humanitarian approaches and refugee studies alike (508). For some time, anthropologists have been challenging this essentialization between displaced people and their homelands, cautioning researchers in their own discipline to recognize home as a cultural construct rather than as being tied to any locality (Appadurai 1988, 37). Equating home with place, they argue, enforces the notion that displacement is a problem in itself, as it upsets the "national order of things" that seemingly manifests between people and place (Malkki 1995). However, nation states and the international community, led by the Western world, are still approaching people on the move from precisely this questionable, static sense. They consider repatriation to be the natural solution to displacement, only taking alternatives of local integration or resettlement into account when the option of returning home is out of question indefinitely (Boer 2015, 493).

Although the humanitarian system considers this to be the natural solution, people do not necessarily want to return to the homes they have left behind. Their feelings towards, and plans about, their previous homes seemed to be dependent on what my interlocutors had experienced before and during flight. Some stated that they would refuse to return to the place they had acquired their disability in by being shot or beaten up. Others reasoned that it was too dangerous to return to Congo due to their limited mobility. Jacob (case 4), for example, explained that it was too risky for him to go back, as he would not be able to flee to the forest at any given moment when an armed group approached. While Bernadette (case 10) was saving money as she wished to return to Congo, her acquaintances advised her not to do so, knowing that she was similarly unlikely to be able to escape from dangerous situations there with her injured back and leg. It was only when Mugenzi showed me a picture of a friend of his in a wheelchair that I heard about a person with a disability who had actually returned to Congo, despite his mobility challenges.

People who had arrived at the camp recently were more likely to think about returning home. As Anette's story demonstrated, some of her neighbours, acquaintances and relatives had already journeyed back to Congo. They were hopeful that they would find their land, familiar structures and relatives in the places left behind. The decision to go back home was, however, dependent on the UNHCR's evaluation of the security situation in certain parts in Eastern Congo. It was illegal for refugees to spontaneously return outside their official repatriation programmes. This meant that people needed money for transport if they aspired to return outside these repatriation structures, which many did not have, as Anette explained. Returning outside these structures was also quite risky. A tragic incident occurred in March 2014, when around 250 Congolese people drowned in Lake Albert when the overloaded boat they had taken on their own initiative to carry them from the Kyangwali refugee settlement to their home relatively close to the border capsized (UNHCR 2014). An individual's decision to return or not was therefore also dependent on what the aid agencies had to offer them.

Apart from the fact that most of the people I got to know in Kyangwali did not want to return to Congo for safety reasons, a sedentary view on displacement was also challenged by the omnipresent displacement in Eastern Congo. It is important to remember that many people had already been 'on the run' in their own country before crossing the border to Uganda. They had previously experienced material and personal loss when their cattle were stolen and their houses burned down, when families were scattered and loved ones disappeared from their lives. Adam, who settled in Kyangwali with his family in 2003, recounted:

> There was already war in Goma in 1990. During that time, we started to run because of that war. And we got used to displacement every year... There was fighting between the rebels and the government so we, the residents, had problems and ran here and there, they chased us, they killed others. From 1996, 1997 we were in a war until 2009.

I do not know whether Adam had lived in a camp for internally displaced people (IDP) during that period, but before I went on a two-week trip to Congo to get a glimpse of the place many of my interlocutors came from, he gave me the names of two of his siblings who lived in one of the IDP camps near Goma. Unfortunately I did not have the chance to meet them, given the official permission I would have needed to visit the camp and the short time of my stay in Congo.

Around 4.4 million people were internally displaced in Congo in 2017, including 1.1 million people in the province of North Kivu alone (OCHA 2017). In a place where areas of violence constantly shifted, it was common for people to move between different locations, including their homes and camps. When I asked my interlocutors where they came from in Congo there was sometimes confusion about their various places of residence at different stages of their displacement. Some had moved to new areas, but still continued to cultivate the fields they had left behind. Others had been hospitalized in faraway towns with war injuries, after which they had never returned to their homes.

The characteristics of Congo's bordering regions with Uganda were another point that challenged a sedentary view of the lives of many people I worked with in Kyangwali. A significant number of my interlocutors had regularly crossed this border before displacement, fuelled by work and education opportunities, or through intermarriage. Especially in the border region of Bunagana, where people spoke similar local languages (Rufumbira and Kinyabwisha), it was common for Congolese people to gain an English-language education, attend the better-equipped hospital, or even cultivate fields on the Ugandan side of the border. Similar interlinkages took place in the border region of Bundibugyo, through which another sizeable portion of my interlocutors had fled to Uganda. As the only Ugandan district which was located west of the Rwenzori mountains, which comprise Congo's natural border south of Lake Albert, Bundibugyo was home to people from the Bakonjo and Baamba societies, which both lived in the two countries' wider border areas. Given this background, even from a sedentary perspective, refugees like Anette and Mugenzi, who had come from the border regions of Bundiugyo and Bunagana, would not necessarily feel culturally uprooted when fleeing to Uganda.

Moreover, Mugenzi and Anette's stories revealed that notions of home change over time. The first time I met Anette, she had expressed her wish to return to Congo. During my fieldwork, however, her husband and the rest of her children joined her in Kyangwali and she seemed to become relatively more settled. She started her work as village vice chairperson, and her son built his own house in their compound. Mugenzi had completely given up all hope of going back after the many years his family had spent in Kyangwali. His life was much more oriented towards the family that had moved to Kampala, like one of his daughters, or abroad, like one of his sisters. As they had already lived in Kyangwali for so many years, Mugenzi's resettlement process was at an advanced stage when I first met him. Hence, people's wish to return, and therefore their notion of home, was subject to change through temporal distance and the alternative future possibilities that became available to them.

Considering that most people in Kyangwali did not necessarily want to return to their home country, why then did they often speak in such positive terms about their previous lives in Congo? Among many people in Kyangwali, home was to a large extent experienced as something from the past that could no longer be home (see also Al-Ali and Koser 2003, 7). Disabled people's narratives about a better life in Congo mostly referred to a time before or between upheavals, or simply to times when people had felt more secure. Also, doubting that "territoriality, rootedness, and memories of violence are necessarily the primary determinants of identification among people on the move", Jansen and Löfving advise caution in understanding people's expressions of nostalgia as a desire to return (2007, 9). While often represented as a "timeless entity in an unchanging context of origin" (9), 'home' should in fact be understood as a constructed narrative about oneself and one's experiences (Eastmond 2007, 255). There were many experiences that people found hard to talk about and tried to block from their memories. Nevertheless, when they spoke about "a life of suffering", they were referring to their lives in Kyangwali. Therefore, the timeless nostalgic version of 'home' served specific purposes. The next section describes people's evocation of their pasts as a way of dealing with their current situation and as a form of their claim-making.

4 "A Life of Suffering": Rather Here than There

When Anette described Kyangwali as "a life of suffering", she brought it up in the context of the role that I or aid workers might play in helping her, or simply to articulate that the conditions in Kyangwali were not good enough to live in and provide a future for her and her family. Anthropologists – most prominently Richard Lee (2012), who identified a "complaint discourse" among the elderly of the Dobe Ju'/Hoansi in Namibia – pay attention to the ways that complaints about the present often go together with an idealization of the past (see also Alber et al. 2008). As a way to describe and possibly also to cope with their current, often very difficult situation, my interlocutors frequently argued that they were suffering more in Kyangwali than they had been in Congo.

When they referred to 'the home that was', they contrasted it with their current situation in which they were foreigners, where they struggled to develop projects or plan for their future, namely, to 'build', as discussed in Chapters 5 and 6 (see also Livingston 2005, 15). In this sense, 'home' was a place and a time in which you owned land that was fertile, where you knew and got along with your neighbours. Disabled people also emphasized the substantial familial support and promising business opportunities of a bygone Congo as a way to describe the "inadequacy of the present" (McKay 2012, 289). Sometimes this was set in contrast to camp life as one that was pervaded by envy, betrayal and mistrust. My interlocutors expressed in some instances that they felt insecure living in a place where people with different national and ethnic backgrounds were gathered. Especially with regard to his sons' poisoning, Mugenzi stressed how careful you had to be in Kyangwali, as you did not know your neighbours well. He explained that he would always say he had already eaten when offered food at somebody's place, to avoid the risk of further poisoning. This resonates with what Ramsay observed among Congolese refugees in Kampala, stating that liking neighbours and even having close relationships with them did not necessarily equate to trusting them (Ramsay 2016, 119). Bernadette (case 10) thought that business had been much easier in Congo, as there she knew where to find products at the best prices and she used trusted people as middlemen to complete her sales.

When people described their life as a refugee, their lack of property featured prominently. Whereas most aspects of "a life of suffering" they mentioned were an issue for all refugees, not having a property was highlighted as being especially problematic for people with disabilities, as Patrick explained: "You know, here we are in a foreign land, we are not in our country. So if you lack money, and when you have nothing like livestock to sell, you cannot pay for casual labour in your fields, so that the children can go to school. Here in the settlement, there is nothing that can help you like that". Although Mugenzi had not spent much time in Congo after his lower legs had been amputated, he similarly explained that the ten fields of timber he had once owned there would have given him enough profit to afford a good education for his children, despite not working in the fields.

Lee and others argue that comparisons with a better past allow people to make claims in the present (2012; see also Alber et al. 2008). I described this form of claim-making in Chapter 3, when the people I talked to for example lauded disability services in Eastern Congo in the same breath as demanding better services in Kyangwali. The many times that people used expressions such as, "here I am, I am just suffering", "you see, all that is here is just suffering, there is no change", or "here I am suffering a lot, because …" signified not only the many challenges that disabled people were going through in Kyangwali, but also pointed to opportunities for claim-making. There was thus a stark tension between the ways people described life in Kyangwali as "a life of suffering", and the possibilities that were available to them in that place due to their refugee and disability status, in comparison to other settings.

In contrast to disabled people who were not refugees, people in Kyangwali seemed to have many opportunities to stake certain claims, and a comparably high chance that these claims would be listened to. One day when I was talking to a man with a paralyzed arm in one of the nearby Ugandan villages, he asserted: "Here we don't have anyone with a metallic crutch. But I see those in the settlement: when someone gets a small injury, he will immediately receive one. But for us, they will put a slab on you … if you heal, good, if you don't.…" The ReHope strategy specified that 30 percent of the refugee assistance should target the host community. All the health centres in Kyangwali were accessible for both refugees and nationals. Yet, while Ugandans could easily access basic health services in these NGO-led health centres, they were not eligible to be considered for more complex health support that required transfers to Kampala for surgery, physiotherapy appointments in Hoima, or assistive devices like wheelchairs or tricycles. These special services funded by the UNHCR were not available to local residents around the refugee settlement. This was also the case in regard to special education for children with disabilities. Only those with refugee status had the opportunity to attend a school for pupils with special needs in another district. In contrast to other contexts, where being categorized as a refugee might bring more constraints than opportunities (see e.g. Janmyr and Mourad 2018), in Kyangwali, the label 'refugee' seemed instead to outweigh any categorical limitations.

This not only played a role for disabled people, but was of more general significance. While Ugandans were able to attend school in the refugee settlement, they were excluded from benefitting from any of the scholarships offered by the aid agencies. One aid worker I knew thought that the local Banyoro people living in proximity to the refugee settlement in Kyangwali found themselves in more challenging circumstances than the refugees, as they did not have access to a comparably good infrastructure, and they could not receive any regular hand-outs like food, money or clothes (see also Chapter 5). Camp life can thus provide opportunities which are not available in places where humanitarian aid is absent. Researchers have observed around other Ugandan refugee settlements that national citizens in these remote areas perceive refugees to be better off than they are (e.g. Nagujja 2014, 26).

Land was also a contested issue between refugees and the local population in Kyangwali. The first time I arrived there I noticed some makeshift tents in a village outside the settlement. Asking about these, I was told that Ugandans themselves had been displaced by the pressure to make space for more refugees. Later on during my fieldwork another makeshift camp of internally displaced people appeared, within what the OPM claimed to be settlement land. While it was officially asserted that the people living on the land had to be evicted to accommodate the great number of newly-arrived refugees (up to 60,000 Ugandans were said to be displaced), many strident voices argued that these land clearances were actually part of the government's plan to secure access to the oil-rich land around Lake Albert (see Matsiko 2013). At the time of my fieldwork the internally displaced Ugandans were not protected by, or provided with services by, the UNHCR.

Moreover, having refugee status instead of national citizenship or being internally displaced could signify opportunities in some cases. It is important to recognize that claim-making was being directed towards humanitarian regimes rather than national governments in this part of the world. The disabled man I talked to in one of the nearby villages expressed this as:

> Concerning us, the disabled people in Bukinda, the way I am, I care for myself. I have to work with this hand of mine to ensure that I survive and feed my family, to ensure that I get my children to school... Even my fellow disabled people, that is the way we are: we have to use a lot of energy since we have no other option... But to say that we shall get extra support from the government, for the disabled, there is no such opportunity. I have never seen such help, I have never seen it.

In both Uganda and in Congo I was told – and observed by myself – that disabled people were more successful in staking their claims to organizations that were funded by international agencies and donors than to their own governments. In Kyangwali, as in other refugee settlements in Uganda, benefits for refugees were much more clearly defined by these organizations, and claim-making could often be more directly practiced than towards the Ugandan government. Hence, being a refugee with a disability signified certain opportunities which were not available in other contexts. This was especially relevant in regard to resettlement, which the next section explores.

5 What the Future Has to Offer

Nearly all the refugees I encountered in Kyangwali dreamt of resettlement and a better life in a Western country.[2] Considered as being 'caught' within a 'protracted refugee situation' and with no viable options for repatriation or

---

[2] During my entire fieldwork period I only came across two people with a disability and a few other refugees who saw their stay in Kyangwali as being permanent. Hanifah and Odongo both said that they would prefer to stay in Kyangwali than return to South Sudan, as the war there had resumed. Most of the South Sudanese refugees had lived for over ten years in the camp, after they were transferred from the Acholi Pi camp in Northern Uganda, at the time it was being attacked by the Lord's Resistance Army (LRA), the Northern Ugandan rebel group led by Joseph Kony. For many of them, their physical memories of their home country lay far behind in the past. Some of the South Sudanese residents I got to know were also able to engage in larger-scale agriculture like tobacco farming over the years, enabled by good relationships with the camp authorities, who allowed them to rent settlement land. As chances of resettlement for South Sudanese refugees in Kyangwali were practically non-existent during the time of my research, imagining a life in the camp maybe also became a more viable option for their future.

permanent local integration, a specific group of refugees had access to resettlement to a third country. On a global scale, especially since the launch of the New York Declaration for Refugees and Migrants in 2016, resettling refugees to a third country had been thought an appropriate replacement for containment in countries of first asylum (Ramsay 2017, 3–4).[3] The reality that only a tiny number of refugees were accepted for resettlement resulted in a struggle over distributing the few resettlement slots (Sandvik 2011, 11). These resettlement slots were only available to Congolese refugees in Uganda, and not to refugees of other nationalities.

At the beginning of my fieldwork I toyed with the idea of leaving the topic of resettlement completely untouched in my research. I thought that it was a research topic in its own right and too much to include within my project, even though everyone brought it up quite prominently in our conversations. Particularly in the months between May and August in 2016, when people travelled to Hoima and Kampala for various interviews and check-ups, and when a number of Kyangwali's refugees left for the US, resettlement was the number one topic of discussion when people met in the market, in a workshop, a bar, or simply on the street.

Almost everyone whose paths I crossed in Kyangwali had an incredibly positive image of resettlement, described by other anthropologists in regard to Congolese refugees in Uganda as a 'blessing from God' (Lauterbach 2014, 291) or 'winning the lottery' (Jacobsen 2005, 55). From the beginning of my fieldwork I found myself somewhat sceptical of the imagined idyllic life in a resettlement country. I doubted that it would be easy for many people I met in Kyangwali to find work in a future resettlement country, adapt to the new environment and deal with racism, especially considering that most of them barely spoke a word of English.

Some of my doubts were confirmed when, some months into my fieldwork, I spoke to a researcher during a conference. She had engaged with Congolese refugees living in Australia after resettling there from Uganda and told me how

---

[3] It is the UNHCR that administers resettlement, but in close partnership with the receiving countries. As described in the *Resettlement Handbook* (UNHCR 2011a), refugees' applications for resettlement are first checked by UNHCR officials, who either refuse or waitlist the applications. For the preliminary accepted applications, representatives of the receiving countries select refugees according to their own specific criteria (Ramsay 2017, 4). Once refugees are accepted for resettlement, the International Organization for Migration (IOM) plays an especially prominent role. The organization provides a three to five day-long cultural orientation on the host countries, and arranges all the pre-departure logistics and exit formalities for the refugees who have been accepted for resettlement (IOM Uganda 2018).

her interlocutors made every effort to maintain the positive image of life in the Western world. In a later publication, she writes:

> Their desire for resettlement was based on the seemingly obvious premise that life in resettlement is better than life as a refugee in Uganda. Resettlement was imagined by many to be a context in which it is possible to create, in their words, a "new life." For many refugees I worked with in Australia, however, this premise is false.
>
> RAMSAY 2017, 6–7

Nevertheless, those who managed to afford a flight back to Uganda after several years would turn up with new clothes and suitcases full of presents, as Ramsay told me the day I met her. Similarly, I saw how young people with whom I was connected through Facebook uploaded pictures that showed them displaying a wad of dollar bills just days after their arrival in the US. Later on came photographs in front of shopping malls or impressive cars.

Disabled people's expectations of life in the US often centred around their disability. Just as Mugenzi had been informed about high-tech leg prostheses, many of my interlocutors shared expectations of better medicine and assistive devices that would enable them to work and eventually forge a better life. This was also evident in the cases of Bernadette (case 10) and Martin (case 9), who hoped that better treatment abroad would enable them to become 'whole' again (see Chapter 6). Claire expressed concern about the timing of her resettlement:

> I am actually praying to God to help us and bless us, so that they don't take us [to the US] when our age is past, just to go and die soon. They should help us when we are still energetic, so that upon reaching there, I believe, my life will change and I will be very well. The thoughts of Kyangwali and Congo will end. Because I know I will dress well, I will receive an artificial arm. Life will be very good.

What again seemed to matter for people's future possibilities were their chances of 'building' and attaining personhood through being able to provide for their families. What my interlocutors had heard from their predecessors was overtly welcoming and free of problems and complications. Yet, despite the inevitable challenges that people possibly preferred not to communicate too openly, there was enough reason for them to hope for family and friends to receive the same opportunity, as Bernadette stated: "Every friend of mine who is there [in the US] is praying for me to get there".

Despite this omnipresent desire for it, resettlement was only a viable option for a few. The UNHCR in Uganda received many more applications than the resettlement placements it could offer. Indeed, on a global scale, in 2016 and previous years, they were able to resettle merely one percent of the country's refugee population, UNHCR's online resettlement data finder shows. This percentage was slightly higher for Congolese refugees in Uganda. Out of the roughly 250,000 Congolese refugees, 4,032 people were resettled in 2014, 4,247 in 2015 and 5,127 in 2016, according to the resettlement data finder. Resettlement was only an option for those who were in a protracted refugee situation, which in Uganda applied only to Congolese refugees, but not to all. Until recently, only people arriving between 1994 and 2005 were considered as being 'protracted', but in 2016 the UNHCR also made the resettlement opportunity available to those who had arrived between 2006 and 2008, if their place of origin or last residence was North Kivu, South Kivu, Katanga or Province Orientale (UNHCR 2018).

In spite of most people's low chances of resettlement, once again the refugee category conferred a very desirable opportunity that non-refugees were not able to attain. This was in particularly stark contrast to the internally displaced people who had settled in and beyond the IDP camps in the Congo and Uganda but did not have any chance of resettlement. Furthermore, refugees who were from countries of origin other than Congo, like Hanifah or Odongo from South Sudan or Vitali from Burundi, had no chance of resettlement apart from one of the special reasons that counted for resettlement entitlement, such as certain protection concerns, marriage and family reunification, medical reasons or discrimination issues (UNHCR 2011a, 197).[4] I was told about cases of fraud, where people of other nationalities – even some Ugandans – had tried to get through the process using a false identity (see also Sandvik 2011).

As the criterion 'refugees with disabilities' had the possibility of being considered under the eligibility category 'specific protection needs and potential vulnerabilities',[5] refugees with disabilities occupied a special status in relation to their resettlement options and future opportunities (UNHCR 2011a).[6]

---

[4] From Uganda, the UNHCR resettled a total of two Sudanese refugees in 2014, six in 2015 and another six in 2016. People of Rwandan or Burundian nationality were not resettled at all from Uganda during this period, as UNHCR's resettlement data finder shows.

[5] This category also included 'women and girls', 'children and adolescents', 'older refugees', 'lesbian, gay, bisexual and intersex (LGBTI) refugees' and 'refugees from minorities and indigenous groups' (UNHCR 2011a, 182–201).

[6] The UNHCR has historically considered resettlement as an option of last resort for refugees with disabilities. According to the 1996 manual called *UNHCR Community Service Guidelines on Assisting Disabled Refugees: A community-based approach*, 'it is more advisable to help

Within the US refugee admission policy, the category 'priority one' for resettlement is for individuals facing compelling safety concerns in their countries of refuge. People in urgent need of medical treatment, as well as people with mental and physical disabilities are included in this category, along with other refugee groups deemed 'vulnerable' (Mirza 2011a, 527). From the UNHCR's side, disability is included under the category of 'medical needs' (UNHCR 2011a). A resettlement officer I talked to in Kyangwali explained that there are three categories of medical needs (emergency, urgent and normal), and that most disabled people were not usually considered to be 'urgent' or 'emergency' cases, as they were used to living with their disability and only needed certain modifications. The UNHCR's 2011 *Resettlement Handbook* states:

> Refugees who are well-adjusted to their disability and are functioning at a satisfactory level are generally not to be considered for resettlement under this category. Only when such disabilities cannot be treated locally or within the UNHCR medical referral scheme, and when they seriously threaten the person's safety or quality of life, should resettlement on grounds of medical needs be explored.
>
> 2011a, 258

Even though the guidance is somewhat restrictive for disabled people, this potential special entitlement left room for a possibility that others without disabilities did not have. For Bernadette (case 10), it was her disability and possibly also her diabetes condition, which required treatment abroad, that eventually brought about her resettlement to the US. Other disabled people were in the process of negotiating their opportunity for resettlement during my fieldwork. Martin (case 9) constantly negotiated with several aid workers about his resettlement needs in terms of treatment possibilities, accompanied by a multitude of medical documents and doctors' recommendations. Filonne, a disabled woman who suffered from incontinence and serious chronic stomach problems, also constantly relayed this link between medical reports and resettlement: "They told me that they had failed, and they gave me a letter stating how they had failed to treat me. They told me that my case has been taken to IOM [for resettlement]". Filonne was of Rwandese origin and Martin was not registered as a refugee for long enough for the standard route, thus both only

---

the integration of the disabled in their own communities' (Mirza 2011a, 526). This has changed, as is evident from the 2004 *Resettlement Handbook*, in which the UNHCR considers disability to be a factor that warrants special opportunities in terms of resettlement (Mirza 2011a, 526).

had any hope of resettlement if they could be considered under the special eligibility criteria. My interlocutors' vulnerability status, both as refugees and as people with disabilities, thus provided them with a double potential opportunity in regard to their future prospects.

The fact that disability was included in the category 'specific protection needs and potential vulnerabilities' was also relevant to some of my interlocutors in terms of potential exposure to jealousy or persecutory actions by others. Examples of these were Jacob's insecurity (case 4), Mugenzi's fear of poison (case 12) and Martin's dwelling (case 9) in the protection house. In her research among Congolese refugees in Tanzania, Marnie Jane Thomson (2012) focused on the official documents that people collected as evidence, given the need to convince aid workers of their persecution and their continuous fear of it. It was especially noticeable how carefully Martin stored his papers that documented his medical problems, but also the court cases and police reports from when his brother had been murdered. Claire (case 7) was resettled earlier than other people, although in her case it was not clear to me if her 'medical needs' or her need for protection following her house being burnt down was the decisive element in this.

For the lucky ones among my interlocutors whose resettlement process had begun, they did not seem too confident in its outcome. They had been disappointed too many times before and they knew that a successful outcome rested on many factors which they could not influence. Disabled people often stated that it was all dependent on God's will, on broader political developments or on the aid agencies, as Mugenzi once commented: "Where they will take us is where we will go. We are used [to it]". Mugenzi experienced this kind of dependency within his resettlement process in a rather unpleasant way. The first time, their process was put on hold because Mugenzi's wife and son were ill shortly before they were due to travel to the US. The process was set back, so they had to apply for a new host state in the US, and did not know about the further procedures and timelines. This was particularly challenging as they had stopped planting new crops and already sold their house and plot, in order to buy suitcases and clothes. The subsequent owner of their house was kind enough to let them stay in exchange for rent. Mugenzi's resettlement case was put off a second time in January 2017 when the US issued its immigration ban under President Donald Trump. The last time I visited him, there were no longer any chickens in his compound, and Mugenzi was disappointedly contemplating returning to Congo, if he was not eventually given resettlement.[7]

---

[7] Mugenzi and his family were eventually resettled in the US in 2018.

Dependency on the aid agencies in regard to people's future prospects was also evident when Anette similarly explained to others that her family was waiting for the "helpers" to tell them what to do, and that it was up to the aid agencies to decide what would happen to them. This resonated with the prevailing sense among many of my interlocutors that the aid agencies were particularly responsible for the well-being of 'vulnerable' people. This was expressed very strongly by Anette's husband, who thought it was the aid agencies' responsibility to care for people "who cannot support themselves". My interlocutors saw the UNHCR especially as their guardian, as some interlocutors expressed: "When we came here, we came through the UN programme", or "they are the ones who brought us here".

How often my interlocutors perceived their situation in regard to home as one of surrendering to the UNHCR's support or decisions can be set in relation to 'the dependency syndrome' that starkly contrasts against ideals of empowerment and independence, as this book has discussed earlier. I would argue that disabled people had a relatively higher dependence on aid interventions as refugees than might be the case in other contexts. The aid targeted at refugees somehow entailed their whole life worlds, as they had lost and left everything behind. Thus, they not only experienced a greater dependency, but also held higher expectations, compared to situations when aid interventions happened in contexts of already established domains of life. Hence, being a "beneficiary", as compared to the concept of clientship (Whyte et al. 2014), was a rather existential condition.

This relatively greater dependence was strengthened by the fact that my interlocutors could not choose between different service providers. Whyte et al. (2014) describe how Uganda's landscape of AIDS treatment is characterized through a 'projectification' of service delivery, and they highlight the ability to choose between different service providers as being a crucial aspect of the concept of clientship. Within relations of patronage, a patron provides material resources but also protection, primarily in exchange for loyalty. If the client's expectations are not satisfied, they can choose to follow another patron, whose services are deemed more appropriate (see also Chabal 2009; Ferguson 2015). Although my interlocutors certainly held expectations about service quality and the logics and practices of aid distribution, their ability to choose between service providers was non-existent.

Yet, the crucial point is that this dependency – however constraining it was – not only shaped my interlocutors' ability to access direct aid which they could invest in their families and businesses, but also determined their search for a home, their pursuit of 'building' a future. It was evident that their status as both refugee, and also disabled, enhanced their possibility of finding a better home. Their orientation towards the aid agencies was of great importance in this regard, and it reflected more of a shared characteristic of their life worlds than their uprootedness from their lost home country or their experience of violence and loss.

6 Conclusion

Disabled people often experienced their life in Kyangwali as one in transit – due to the contested temporality of the camp that neither supported a permanent stay, nor offered other long-term solutions for many people – a situation that was incisively expressed in the phrase "our heart does not settle". This chapter has looked at how people remembered their past, how they interpreted their current situation, and how they imagined their future.

The chapter challenged a sedentary view on displacement, which was prevalent in the aid agencies' approaches towards refugees. People did not want to return for manifold reasons, including their limited mobility to flee again and the often painful memories of the circumstances in which they had acquired their disability. A sedentary view was also challenged through the omnipresence of internal displacement in Congo, as well as the characteristics of the country's border region with Uganda. As people from those regions had commuted across the Ugandan borders for ages and sometimes shared a language with their neighbours, and since refugees in Kyangwali often had familial ties not only to Congo, but also to Kampala, other refugee camps in Uganda, or Europe and the US, my interlocutors' notion of 'home' was not necessarily tied to a common place of origin.

Despite the sometimes horrific and tragic experiences my interlocutors had gone through during war and flight in Eastern Congo, when they spoke about "a life of suffering", they were referring to their current life in the camp, while remembering a better past. My interlocutors strongly oriented themselves towards the aid agencies and their representatives because of what they had to offer: whether that was supporting them to move back home, providing them with the opportunity of resettlement, or offering them economic or educational possibilities to make their life in the camp more bearable. Disabled people's refugee status gave them additional opportunities in comparison to disabled Ugandan citizens, who lacked extra support from the government in terms of medical treatment, assistive devices or educational possibilities.

Nearly every refugee aspired for resettlement, leading to a better future in Europe or the US. Many disabled people based this wish on their hope of better medical treatment, or prostheses that would enable them to walk or work.

Whereas resettlement was only a viable option for a few refugees, the option was closer to grasp for disabled people, due to their vulnerability status. Their disabled status provided a potential opportunity that was out of reach for refugees without disabilities, or for disabled Ugandan nationals in Kyangwali's surrounding villages. Although the possibility of resettlement was more attainable for people with disabilities than for non-disabled refugees, it might still be somewhat utopian in many other respects, and one that people had to invest a lot of time and energy into negotiating for.

Throughout this book I have argued that disability held a particular place in the refugee settlement, because an individual's body became important for their pursuit of 'building' families and projects in Kyangwali. This chapter has demonstrated that disability had the same significance in regard to searching for a home and thus 'building' a desirable future. This required permanent interaction with the aid agencies which revealed that, in addition to the various changes and losses that happened through displacement, the patterns of relations between refugees and aid agencies indicated important shared particularities of their life worlds. This book thus contributes to the literature that describes people's experiences of humanitarian interventions as very characteristic in the lives of refugees, and the ways they imagine their own futures.

CHAPTER 8

Considering a Different Logic of Distribution

This book has explored what it means to live with a disability in a refugee settlement in Uganda at a time that is undergoing a paradigm shift in regard to how disability and its assumed vulnerability are perceived within the humanitarian agenda, and how it should best be addressed. My point of entry for this overall research question was the description of the closing event of Aid Global's project in Kyangwali. This 'unequal encounter', as I described the event, put the relations between disabled people and aid agencies in regard to their ideas and values about distribution at the heart of this book. My arguments were therefore built around the principles upon which someone is entitled to assistance and resources, and can claim for them, which I call the 'logics of distribution'.

I approached my research question through the analytical lens of interdependence, and thus adapted a theoretical perspective that is relevant to both distribution and personhood. Ferguson's take on patron-client relations and especially his concept of 'distributive labour' helped me to better understand my interlocutors' positioning and claim-making towards the aid organizations. Whyte et al.'s concept of 'clientship' gave me a relevant insight into the morality of exchange that takes place at different levels within the aid system. It was then Livingston's concept of 'building' which allowed me to put my observations into the broader context of disabled people's personhood in this setting. Alongside the chapters that have discussed the domains of food, shelter, care, work, body and home, I have examined several more specific and broader categories which play a role within these domains, and analyzed the ways that humanitarian aid is entangled with disabled people's socialities.

With this focus on the social and institutional conditionalities that shaped disabled people's life in a refugee settlement, I intended to challenge and diverge from the prevalent discourse on refugees with disabilities that perceives them predominantly as being 'doubly vulnerable' (e.g. Karanja 2009; Reilly 2008; Smith-Khan et al. 2014). As there is a shift towards a rights-based approach in relation to disability in the humanitarian world, I also investigated what this shift meant for people with disabilities in the setting of a refugee settlement. At the outset of this book I drew on a statement that a Ugandan government official had made about Aid Global's project. He summarized the project's outcome by saying: "they [people with disabilities] are now recognized, respected as full and equal members of society, with increased self-esteem and reduced dependence on other people". By now, the reader might have a different view of what this recognition as full and equal members of society or reduced dependence actually meant for people with disabilities in Kyangwali. This final chapter sums up the alternative perspective on these matters which runs through this book, considers the relevance of my insights, and reflects on some of their possible practical implications.

1 The Ambivalent Role of Humanitarian Aid

Even in its very basics, Uganda's refugee policy context presented great challenges for people with disabilities. Its settlement approach required people to not only build their own homestead on their allocated land, but also to become self-reliant through agriculture, both of which exceeded many disabled people's capacities, by virtue of their bodily conditions. The support the aid agencies offered to 'people who cannot help themselves' was first and foremost about provision, for instance in the form of special food rations. However, this institutional support fell short in terms of crucial everyday activities such as fetching water, collecting firewood or cooking. By promoting an entirely agricultural economy in quite remote areas, disabled people were also largely excluded from engaging in economic activities. Possibilities for business were severely limited, and many of my interlocutors were not easily able to pursue the kinds of work they used to do in their home country.

Humanitarian aid provided through the vulnerability categories strived to compensate for the exclusionary features that Uganda's self-reliance strategy and refugee settlement policy involved for disabled people. In several chapters of this book I have demonstrated how the categorization approach did not fulfil its intention of compensating for people's identified vulnerabilities. This was particularly evidenced by the example of food assistance. The way food aid was provided hardly counted as compensation, as its quantity only ensured people's survival, but was not in any way equivalent to what an able-bodied person could procure through agricultural activity. As long as this measure is considered as a compensation, however, the service providers, most notably the WFP, would do well to adjust the amount of food provided to people with disabilities. This would support them in a way that would give them a more equal opportunity with non-disabled refugees to also meet other needs and support their families.

Yet, despite the many shortfalls of humanitarian aid for disabled people in Kyangwali, I have also revealed that aid nevertheless played a very crucial role in my interlocutors' lives – in sometimes surprising ways. Although they were excluded from the humanitarian system in many regards, and although they experienced challenges that emerged from having lost social ties and property through displacement, I have argued in this book that a person with a disability might find that living in a refugee settlement also provided some important opportunities. This book has offered a valuable ethnographic account of twelve individuals who were living with different kinds of disabilities in Kyangwali – a description that diverges from, and even counters, the widespread perception that disability places people at the very margins of an already disadvantaged group. I observed that, in a refugee settlement, a person's body could become an important resource in their pursuit of 'building' relations, projects and futures. The strong and prevalent desire for a future in a third country in particular was an opportunity that was not open to many non-disabled refugees or people without refugee status. There was a special value attached to disability, which could lead to a change in social position and attention. Thus, I have argued in this book that increased potential access to aid repositioned disabled people in the refugee settlement, because it made them become valuable connections for others.

2 Ignored and Overlooked Dependencies

The ambivalences revealed around humanitarian aid for disabled people also alludes to some critical issues in regard to dependency. This book concludes that the dependence/independence dichotomy that directs so much work on refugees with disabilities is not of much use, and is sometimes even misleading, when one problematizes certain situations. Throughout the different chapters of this book I have taken a diverse range of social and material dependencies into account, building on the premise that people and institutions are always found to be mutually dependent, although this is often on very unequal terms. Even though I propose that it is analytically as well as empirically more useful to think and talk in terms of interdependencies, it is inevitable that I have drawn on the dichotomies myself in order to problematize the phenomenon of dependency. My reflections in this and the next section are relevant not only for refugees with disabilities, but for refugees and humanitarian assistance more broadly, and similarly within approaches towards disability that find influence in development and aid projects across the global South.

During my entire fieldwork experience, the problematic talk of dependency by representatives of aid organizations was mainly centred around my interlocutors, or towards the refugee population at large. Furthermore, policy research predominantly focuses on the problem of dependency among disabled people and refugees more generally. Through my lens of patron-client relations, I was able to draw attention to the ways that the aid workers and aid agencies in Kyangwali were also always situated within various relations of interdependence. This focus was important in order to understand how distribution for disabled people worked in Kyangwali. In line with Whyte et al.'s (2014) concept of 'clientship', I demonstrated that the various aid agencies in Kyangwali were dependent on disabled people to provide information during assessments, to sign for the aid distributed, to attend certain events, to be photographed and filmed for reports and promotional material, and to submit to the aid organizations' working procedures. The aid workers and aid agencies relied on this cooperation from disabled people in order to produce the necessary paperwork for their own exchange relations with their donors. They were also dependent on my interlocutors in a more abstract sense, since 'having people' with disabilities ensured the flow of resources and brought them the opportunity to generate new projects.

My research contributes to the literature on patron-client relations in institutions and projects, as it emphasizes people's relatively greater dependency on institutions that existed in the context of a refugee settlement. As refugees were expected to create a home and social existence in a refugee settlement, intervention was taking place in less established life worlds than in settings where much other research in this field has been carried out. Compared to HIV/AIDS clients, for example, my interlocutors in Kyangwali lacked any possibility to choose between different service providers. The ability to choose is, however, a crucial aspect within the workings of patron-client relations, so its absence created a greater dependency. Further research would gain from a comparative perspective that focuses more on similarities and differences in regard to the kind of dependencies that aid recipients experience through different kinds of aid interventions.

My research also uncovered a very interesting aspect of dependency within the eligibility criteria for special aid. Although the ways people with bodily challenges were defined, assessed and categorized in Kyangwali indicated a largely medical understanding of disability, people's inability or vulnerability was not just defined physically. When people were categorized as being eligible for special assistance under the EVI or PSN categories, their social relations were taken into account. For instance, an individual would only qualify for special food aid or shelter construction if their bodily constitution prevented them from fulfilling specific tasks and if they also lacked the social support to do so.

The book has revealed some of the critical consequences that this kind of categorization produced. By closely scrutinizing everyday concerns and practices around food, I was able to show that the eligibility criteria for special food aid ran the risk of widening the gap between those who were dependent and those who were able to provide. The people who received food rations could contribute them to their families, or could sell a portion of them to pay for their children's school fees. With family support as an exclusionary criterion for special food aid, though, disabled people who did have families were assumed to be entirely dependent on their social networks, which therefore removed their ability to contribute their part. Thus, the criteria for food aid did not support them in their role as providers.

The criteria for distributing aid also endorsed a highly gendered dimension of dependency. This became particularly evident through the example of how assistance for special shelter construction was provided. An able-bodied husband was expected to construct a house, while an able-bodied wife was not. This gendered logic of distribution assumed that women were dependent on their husbands, leaving them even more vulnerable. Some of my female interlocutors expressed their fear of being abandoned by their husbands if they were made entirely responsible for every kind of support towards their family.

The aid agencies in charge of the categories' respective definitions should recognize these critical outcomes and adjust their criteria to resolve them. People with disabilities, especially women, should in no way be made even more dependent because they are expected to rely on their families and husbands. Often, frontline aid workers had already adopted the criteria in practice, given their obvious limitations, for example, when they did not confine themselves to solely taking into account a person's social relations as indicated on their attestation papers, but also considered how much a person was actually being supported through these social relations. The highly critical dependencies created by the current eligibility criteria for special aid, as exposed by this book, provides further important grounds for amending the criteria. Aid workers on the ground should be consulted and their experiences integrated for this task. Adjusting the criteria in these ways might be difficult to achieve, however, as the vulnerability categories' focus on social relations is deeply rooted in an overall concern to prevent people's dependency on aid.

3 Enabled through Aid, Rather than Dependent

My ethnography of disabled people's lives in Kyangwali has clearly demonstrated that the overall premise of preventing aid dependency runs the risk of accepting – or even reinforcing – other forms of dependency. The aid agencies' attempts to avoid aid dependency placed the emphasis on disabled people being cared for not only by their families and spouses but also, as much as possible, by 'the community' – especially for crucial everyday activities such as fetching water, collecting firewood or cooking, but also for things like constructing a hut, for example. Responsibility was put onto the community social workers, and especially onto faith-based congregations. Any kind of help which went beyond basic provision was only offered as an absolute last resort by the aid agencies. This community-based approach has proven difficult in reality, though, especially in the absence of extended kinship ties and the precarious situation many refugees in Kyangwali found themselves in. The approach also faced challenges of trust and obligation in the diverse social environment of a refugee settlement, where people who had not known each other before suddenly began living side-by-side as neighbours. The community-based approach accepts that disabled people are heavily dependent on others' ability and willingness to help them and does not problematize certain, sometimes critical, dependencies of disabled people from the communities they live in.

This insight brings about practical considerations. The aid agencies should recognize the limits of the community-based approach, and especially consider what are its actual consequences for people with disabilities. In order to avoid too many chances for people with disabilities to develop problematic dependencies on their families or the community, aid agencies could consider taking on more responsibility as institutions for the situation of people with disabilities and supporting them in a similar way that is the case in countries with well-developed social systems – for example, by paying caregivers or paying financial contributions similar to social grants directly to the person who needs additional support.

As community-based approaches also form an imperative in how disabled people are viewed and approached within the global South at large – mainly along the concept of 'community-based rehabilitation' – my research insights around critical dependencies could be enlightening for other settings as well. Even though who and what exactly 'the community' is differs in every context, a critical investigation into the consequences of prioritizing community support over individual aid provision is important either way.

Another significant strategy which the aid agencies employed to prevent or reduce aid provision lay in the emphasis they placed on an individual's responsibility to become economically productive. For this purpose, the aid agencies relied heavily on livelihood training sessions, workshops, and sensitization around disabled people's economic empowerment. They despised aid donations that exceeded people's basic needs, assuming that this would lead them into a problematic dependency on aid and that this would lead them to stop doing anything to increase their own productivity. However, the book has revealed that, instead of creating a very problematic dependency on donors as is so often assumed, access to aid actually empowered people in various ways, as it helped them to invest both in projects such as business or education, and in important relations. I have shown how aid enabled people to become more independent in economic terms instead of reducing their motivation to work and create.

This observation of how important aid was for my interlocutors' pursuit of their 'building' endeavours is in direct contrast to much of the literature that engages with the so-called 'dependency syndrome', describing aid organizations' fear that aid will create passivity and excessive demands (see Harrell-Bond 1986; Malkki 1992; Nabenyo 2019). Even though this perception that aid makes people dependent has been challenged, most of this literature still perceives aid dependency as something intrinsically problematic (e.g. Bakewell 2003; Hyndman 2000b; Kibreab 1993). Ferguson's (2015) work on valuing dependency differently than being inherently negative was very important for my study, as he draws attention to desired forms of dependency, especially with his concept of 'distributive labour'. In my fieldwork, I clearly found that certain kinds of dependency could instead signify a sign of connectedness and belonging that, importantly, enabled people to make claims for assistance.

Being able to invest in such desired relations of interdependence was particularly significant for disabled people who had been forcibly displaced. As they had often lost track of, or been separated from, family and other carers through their flight from their home countries, the creation and cultivation of such relations in the refugee camp became an even more vital activity. People living in the settlement without any family often received care more readily from non-kin community members, who appreciated the reliability of disabled people's regular food rations, for example. Direct aid did not have the effect of making people with disabilities less supported and valued in their community. Rather, the opposite was the case. The aid agencies should appreciate the difference that access to aid makes for people with disabilities in receiving care within their communities, and adjust their approaches accordingly, by opting to provide more generous assistance, instead of being driven by their misguided fears.

Nonetheless, my interlocutors did not aspire to engage in all forms of interdependence. In some situations, people with disabilities embraced independence in line with a sustainable development discourse, whereas in others they claimed it was the aid agencies' responsibility to fully provide for them and look after their well-being. This apparent tension only makes sense by differentiating various forms of dependence and independence and recognizing how these shape one another. My interlocutors strived to achieve economic autonomy and financial freedom in many ways, and the setting of the refugee camp, rather unexpectedly, offered some interesting opportunities for this. Reduced familial ties enabled individual freedoms, because people were less confronted with distributive claims from an extended network of kin, whilst at the same time regular aid supported their economic endeavours. Ferguson does not pay much attention to such personal aspirations for people's own individual development or those of a core family. Thus, my insights from a refugee settlement environment might be valuable for understanding more differentiated views of interdependencies in other research contexts as well.

Given the complexities of these interdependencies, it is not sufficient to determine whether an individual was dependent or independent. Both were intertwined – access to aid enabled people's personal aspirations to become economically productive, to provide for their family, and to plan better for their future. Even though aid had this potential to support people in their pursuit of 'building', however, this was frequently undermined by the many moments at which my interlocutors found themselves in what I describe as situations of 'disappointed recognition'.

4 Disappointed Recognition

I have demonstrated in this book how the aid agencies' working procedures shaped my interlocutors' perceptions of distribution and their entitlement to aid. The multiplicity of recurrent bureaucratic procedures they had to undergo – be it in participatory assessments that aimed to integrate refugees' perspectives into service delivery, the diverse categorization processes, or assessments for special shelter construction or assistive devices – all implied to my interlocutors that their concerns were being recognized and attended to. In such procedures disabled people expressed their wish to be supported with their children's school fees, their need for a new house, or their lack of household items like soap or salt. They believed that measuring their bodies or undergoing medical examinations would lead to them receiving an appropriate assistive device or the required medicine. What followed after these exercises in terms of actual aid, however, often dashed people's expectations, when the expressed problems were not solved, or the requested material not delivered. Hence, mistrust that the aid agencies and their workers were corrupt was a common attitude among my interlocutors, and a way for them to consolidate the aid agencies' assumed responsibilities according to their understanding of a moral logic of exchange.

Such situations of disappointed recognition seemed to be a problem generally in the refugee settlement. Yet, importantly, my research points to the possibility for these situations to become exacerbated for disabled people and other perceived vulnerable groups, because of an increasing focus on the rights-based approach. As promising as it is, when people are taught about their rights and sensitized about the importance of their economic empowerment, or when they are encouraged to participate as equal members of society, the limits of the aid provided in reality might prove even more disappointing.

Situations of 'disappointed recognition' were not only found in the ways people were treated through these working procedures in Kyangwali, they also played a role at a broader level. The very act of registration implied to my interlocutors that the aid agencies had assumed responsibility for their well-being and future. This perception indicates a deeper social logic that people had in terms of distribution, where they understood the aid agencies as patrons who were required to fulfil certain obligations, and towards whom they could stake their claims. It is important to appreciate here that aid for refugees targets their entire life worlds. People were eligible for support because they did not have anything. This made access to aid and thus their relation to the service providers a very existential issue.

Aid agencies are strongly recommended to take seriously this other logic of distribution, in which disabled people see them in the role of patrons who must, to some extent, fulfil their expectations, given the manifold exchange relations at hand. This would allow them to understand the short- and longer-term implications of their working procedures and how they affect the often very tense interactions between aid workers and disabled people, and refugees in general. Aid workers should improve communication and put much more effort into providing timely, informative feedback to disabled people about their various assessments. Furthermore, the aid agencies should carefully consider the need for, and implications of, each assessment, and question who it really serves.

As such unequal yet interdependent relationships exist in any situation where aid is delivered and development promoted, these insights into how my interlocutors understood their position in the aid system are also highly relevant to other contexts. The findings are not only an important contribution to the discussion of humanitarian and development aid more generally, but also to basic inquiries in anthropology, as they connect the questions about aid with issues of personhood as they relate to the exchange of material goods and care.

5 Towards a Post-Rights Approach to Dependency

Throughout this book I have questioned the relevance of a rights-based approach for my interlocutors. Along Eckert's (2011) perception of citizenship as something that is fundamentally social, I have drawn attention to the ways disabled people understood their entitlement in their relations with the aid organizations, and how they made claims within social interactions and through 'comparative benefits'. People with disabilities positioned their claims in relation to the community social workers or other aid workers they interacted with. They did not talk in terms of rights when expressing their demands for support, but gave comparisons to the kind of support they had been given at other points in time and in other settings, or what other people around them had received.

This comparative aspect of making claims is especially innovative within anthropological literature, as it demonstrates the irrelevance of a rights-based approach for disabled people in certain settings from a further viewpoint. In the specific context of a refugee settlement, where aid was channelled through a hierarchical set of categories and where people lived in such close proximity to each other, these 'comparative benefits', as I term them, gained great importance. Further research on the consequences of a rights-based approach might consider the more fundamental question of how far disability is understood as a state of being that requires special support, and from whose perspective. Stone writes that it is an often unquestioned and 'modern' perception that disabled individuals should be compensated through collective resources (1986, 26, 174). Ferguson emphasizes that people have a conception of rightfulness which is separate from a reference to rights (2015, 50). During my research in Kyangwali it was difficult to assess how far disabled people perceived their entitlement in relation to what was being offered by the aid agencies, which they could practically claim for, or if they saw it more in terms of what they considered 'rightful', due to their own particular logic of distribution. Further research would gain from exploring the interplay of rights and rightfulness when studying the relevance of a rights-based approach in various settings.

Although I have questioned the relevance of a rights-based approach for my interlocutors, I also observed that claim-making seemed to be more possible for disabled people in Kyangwali than for people with disabilities living around the remote environs outside the refugee camp. Further research would have to thoroughly engage with an anthropology of rights and relate the findings of this specific case of refugees with disabilities to critiques of human rights more broadly (e.g. Englund 2006).

This book is also a contribution to the anthropological studies which engage with the influence of rights-based approaches on disability in other settings, but also in development aid more broadly, for it shows how the gains of this approach mainly lay in the aid agencies' hands, and that it undermined a redistribution of resources. To stress this, I will return one last time to Aid Global's project, to ask who this approach made a difference for in the longer term. What sustainable solutions are – or should be – took divergent forms among people with disabilities in Kyangwali and Aid Global's project implementers. The project certainly provided aid that was sustainable in some respects: the beneficiaries may retain the knowledge provided about rights and hygiene, the advocacy and sensitization may increase within a wider audience, and the inclusive boreholes may provide water for future generations in Kyangwali. Also, the project was officially handed over to the governmental camp authorities in a two-day workshop that catered for a large number of government, UN and NGO representatives. The workshop's costs totalled 30 million Ugandan shillings[1] of Aid Global's project money. Special cooperation groups were formed between these different partners, and possibilities for more engagements with disabled people were set in the direction that disability might be given more attention in future.

However, neither Aid Global nor the European government that funded this project have earmarked funds for any future activities. And, despite good intentions to carry on with the project's aims, aid workers and people with disabilities equally knew that, without money, there would not be any future meetings or service delivery. Considering the sum of money spent on the endeavour to fit what the aid agencies and donors perceived as sustainable solutions – by handing over a project in this way – one might wonder what difference an alternative logic of distribution could have made for my interlocutors.

I have argued in this book that the shift towards a rights-based approach for refugees with disabilities ran the risk of undermining redistribution, and even increasing the inequalities that already existed between service providers and people with disabilities – despite its discourse of equality and independence. The book thus also speaks, like much work before it, to the unintended, often undesirable consequences of humanitarian aid. My contribution in

---

[1] Approximately 8,200 US dollars.

this regard lies especially in my engagement with the rights-based approach. Anthropological work on humanitarianism that focuses on the body emphasizes the dangers of a depoliticization, asserting that medicalization deflects from issues of social justice and redistribution (e.g. Fassin and D'Halluin 2005; Ticktin 2006; Fassin 2012). In my specific research context, the dynamics of this discourse development seemed to be turned upside down, with the similar consequences that social justice and redistribution are being averted.

The rights-based approach is a very important step, but in order to fulfil its aims, support for disabled people in this setting should go further, and concentrate more concretely on direct aid rather than sensitization, merely formal recognition or token participation. This is because one of the consequences of the current rights-based approach is, unfortunately, that disabled people have less chance to actually access material and financial assistance. If the rights-based approach is to provide empowerment and opportunities as equal members of society as it promises, then the aid agencies should support disabled people with material and financial assistance that go beyond their basic needs.

Certain approaches in the development world at large are increasingly emphasizing the need for aid to reach the targeted population more directly. This has been tested in several pilot projects around a basic income grant, which point to a similar direction as my research on refugees with disabilities. Like my interlocutors in Kyangwali, people more generally are well aware of how to spend money for their own good, and care provided for 'vulnerable' people by the communities they live in is unlikely to decrease if more aid is provided. Yet, these approaches are also encountering resistance, as the aid agencies are wary of leaving individual beneficiaries to decide how to use their resources, and because demands for direct aid contrasts so starkly with the ideal of an empowered and independent understanding of personhood. Considering such a different logic of distribution seems an even bigger challenge when focusing on disability, because of the close entanglement of disability approaches with a Western disability movement that promotes universal individual rights and independence.

I assert that this resistance against direct aid is somewhat contradictory. On the one hand, people are not actually recognized as equals, since the aid agencies withhold the overarching distribution of resources, whereas on the other hand, this attitude is supported by their rejection of a scenario which casts beneficiaries in the role of dependents. The different logics and practices of distribution discussed in this book reveal the abstract nature of ideals of equality and independence, and how its advocacy risks obscuring both important and problematic realities of patronage and dependence. Aid interventions that promote a more direct form of assistance will, of course, create new forms of dependencies, which cannot easily be anticipated. Therefore, there is a need for more thorough empirical research that focuses on questions of dependence, independence and interdependence in relation to such a different logic of distribution.

Bibliography

Ablon, Joan. *Little People in America: The Social Dimension of Dwarfism.* Westford: Praeger, 1984.

Adelman, Howard, and Astri Suhrke. *The Path of a Genocide: The Rwanda Crisis from Uganda to Zaire.* Piscataway: Transaction Publishers, 1999.

Agamben, Giorgio. *Homo Sacer: Sovereign Power and Bare Life.* Redwood City: Stanford University Press, 1998.

Agar, Michael. *The Professional Stranger: An Informal Introduction to Ethnography.* Cambridge: Academic Press, 1996.

Agier, Michel, and David Fernbach. *Managing the Undesirables: Refugee Camps and Humanitarian Government.* Boston: Polity, 2011.

Al-Ali, Nadje, and Khalid Koser. *New Approaches to Migration? Transnational Communities and the Transformation of Home.* London: Routledge, 2003.

Alber, Erdmute, Sjaak van der Geest, and Susan Reynolds Whyte. *Generations in Africa: Connections and Conflicts.* Münster: LIT Verlag Münster, 2008.

Altermark, Niklas. *Citizenship Inclusion and Intellectual Disability: Biopolitics post-institutionalisation.* London: Routledge, 2018.

Appadurai, Arjun. "Putting Hierarchy in Its Place." *Cultural Anthropology* 3, no. 1 (1988): 36–49. https://doi.org/10.1525/can.1988.3.1.02a00040.

Arendt, Hannah. *The Origins of Totalitarianism.* Boston: Houghton Mifflin Harcourt, 1973.

Bakewell, Oliver. "Community Services in Refugee Aid Programmes: The Challenges of Expectations, Principles, and Practice." *The Fletcher Journal of International Development* 18 (2003): 5–18.

Bakewell, Oliver. "Research Beyond the Categories: The Importance of Policy Irrelevant Research into Forced Migration." *Journal of Refugee Studies* 21, no. 4 (2008): 432–53. https://doi.org/10.1093/jrs/fen042.

Barnartt, Sharon N. "Disability as a fluid state: Introduction." In *Disability as a Fluid State* (Research in Social Science and Disability 5), edited by Sharon N. Barnartt, 1–22. Bradford: Emerald Publishing, 2010. https://doi.org/10.1108/S1479-3547(2010)0000005003.

Beckmann, Gitte, "Competence for Citizenship: Deaf People's (Re)creation of Polities and Claim-Making Possibilities in Northern Uganda." PhD diss., University of Zurich, 2018.

Berghs, Maria. *War and Embodied Memory: Becoming Disabled in Sierra Leone*. Fanham: Ashgate Publishing Company, 2012.

Berghs, Maria. “Radicalising ‘disability’ in conflict and post-conflict situations.” *Disability & Society* 30, no. 5 (2015a): 743–58. https://doi.org/10.1080/09687599.2015.1052044.

Berghs, Maria. “Disability and Displacement in Time of Conflict: Rethinking Migration, Flows and Boundaries.” *Disability and the Global South* 2, no. 1 (2015b): 442–595.

Betts, Alexander, Louise Bloom, Josiah Kaplan, and Naohiko Omata. *Refugee Economies: Forced Displacement and Development.* Oxford: Oxford University Press, 2017.

Betts, Alexander, Naohiko Omata, and Olivier Sterck. “Self-Reliance and Social Networks: Explaining Refugees’ Reluctance to Relocate from Kakuma to Kalobeyei.” *Journal of Refugee Studies* 33, no. 1 (2020): 62–85. https://doi.org/10.1093/jrs/fez084.

Biehl, João Guilherme. “The Activist State: Global Pharmaceuticals, AIDS, and Citizenship in Brazil.” *Social Text* 22, no. 3 (2004): 105–32. Project MUSE.

Biehl, João Guilherme. *Will to Live: AIDS Therapies and the Politics of Survival.* Princeton: Princeton University Press, 2007.

Boer, Roselinde Den. “Liminal Space in Protracted Exile: The Meaning of Place in Congolese Refugees’ Narratives of Home and Belonging in Kampala.” *Journal of Refugee Studies* 28, no. 4 (2015): 486–504. https://doi.org/10.1093/jrs/feu047.

Brankamp, H. “‘Occupied Enclave’: Policing and the Underbelly of Humanitarian Governance in Kakuma Refugee Camp, Kenya.” *Political Geography* 71 (2019): 67–77. https://ora.ox.ac.uk/objects/uuid:21adf2de-233a-4ec6-b3b4-7c25973d8fa8.

Bruner, Edward M. “Experience and its Expressions.” In *The Anthropology of Experience,* edited by Victor W. Turner and Edward M. Bruner, 3–30, Champaign: University of Illinois Press, 1986.

Carsten, Janet. Cultures of Relatedness: New Approaches to the Study of Kinship. Cambridge: Cambridge University Press, 2000.

Chabal, Patrick. *Africa: The Politics of Suffering and Smiling.* London: Zed, 2009.

Chabal, Patrick, and Jean-Pascal Daloz. *Africa Works: Disorder as Political Instrument.* Melton: James Currey Publishers, 1999.

Clark, Christina R. “Understanding Vulnerability: From Categories to Experiences of Young Congolese People in Uganda.” *Children & Society* 21, no. 4 (2007): 284–96. https://doi.org/10.1111/j.1099-0860.2007.00100.x.

Clark-Kazak, Christina R. *Recounting Migration: Political Narratives of Congolese Young People in Uganda.* Montreal: McGill-Queen’s Press, 2011.

Clemens, Michaela S. “Participant Observation at Buduburam Refugee Settlement, Ghana: Fatigue, Fevers, and Food Rations.” *Practicing Anthropology* 30, no. 3 (2008): 33–37.

Cole, Georgia. “‘But If Locals Are Poorer than You, How Would You Justify Additional Help?’: Rethinking the Purpose of Sensitive Interview Questions.” *Refugee Survey Quarterly* 37, no. 3 (2018): 328–52. https://doi.org/10.1093/rsq/hdy010.

Comaroff, John L., and Jean Comaroff. "On Personhood: An Anthropological Perspective from Africa." *Social Identities* 7, no. 2 (2001): 267–83. https://doi.org/10.1080/13504630120065310.

Constable, Nicole. "The Commodification of Intimacy: Marriage, Sex, and Reproductive Labor." *Annual Review of Anthropology* 38, no. 1 (2009): 49–64. https://doi.org/10.1146/annurev.anthro.37.081407.085133.

Couldrey, Marion, and Maurice Herson, eds. "Disability and displacement." *Forced Migration Review* 35 (2010). https://www.rsc.ox.ac.uk/publications/disability-and-displacement.

Crenshaw, Kimberle. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum* (1989): 139–68.

Crock, Mary, Christine Ernst, and Ron McCallum. "Where Disability and Displacement Intersect: Asylum Seekers and Refugees with Disabilities." *International Journal of Refugee Law* 24, no. 4 (2012): 735–64. https://doi.org/10.1093/ijrl/ees049.

Crock, Mary, Laura Smith-Khan, Ron McCallum, and Ben Saul. *The Legal Protection of Refugees with Disabilities: Forgotten and Invisible?* Northampton: Edward Elgar Publishing, 2017.

Dahl, Bianca. "'Too Fat to Be an Orphan': The Moral Semiotics of Food Aid in Botswana." *Cultural Anthropology* 29, no. 4 (2014): 626–47. https://doi.org/10.14506/ca29.4.03.

Daniel, E. Valentine, and John Chr. Knudsen. *Mistrusting Refugees.* Berkeley: University of California Press, 1995.

Danish Refugee Council (DRC). "'To Have Peaceful Coexistence, People Need to Have Full Stomachs': Rapid Conflict Assessment in Kyaka II Refugee Settlement, Uganda". 2018. https://drc.ngo/media/4585938/drc-may-2018-kyaka-ii-rapid-conflict-assessment_for-release.pdf.

Das, Veena, Arthur Kleinman, Margaret M. Lock, Mamphela Ramphele, and Pamela Reynolds. *Remaking a World: Violence, Social Suffering, and Recovery.* Berkeley: University of California Press, 2001.

Davis, Austen P. "Targeting the Vulnerable in Emergency Situations: Who Is Vulnerable?" *The Lancet* 348, no. 9031 (1996): 868–871. https://doi.org/10.1016/S0140-6736(96)02134-4.

Devlieger, Clara. "Rome and the Romains: Laughter on the Border between Kinshasa and Brazzaville." *Africa* 88, no. 1 (2018a): 160–82. https://doi.org/10.1017/S0001972017000614.

Devlieger, Clara. "Disability." In *The Open Encyclopedia of Anthropology*, edited by Felix Stein, Matei Candea, Hildegard Diemberger, Sian Lazar, and Joel Robbins. Facsimile of the first edition in The Cambridge Encyclopedia of Anthropology, 2023. https://doi.org/10.29164/18disab.

Devlieger, Clara. “Contractual Dependencies: Disability and the bureaucracy of begging in Kinshasa, Democratic Republic of Congo.” *American Ethnologist* 45, no. 4 (2018c): 455–69. https://doi.org/10.1111/amet.12701.

Dick, Shelly. “Review of CORD community services for Congolese refugees in Tanzania”, 2002. UNHCR. https://www.unhcr.org/sites/default/files/legacy-pdf/3d81ad774.pdf.

Douglas, Mary. *Purity and Danger: An Analysis of Concepts of Pollution and Taboo.* London: Psychology Press, 2003.

Drotbohm, Heike and Erdmute Alber. “Introduction.” In *Anthropological perspectives on Care: Work, Kinship, and the Life-Course*, edited by Erdmute Alber and Heike Drotbohm, 1–19. New York: Palgrave Macmillan, 2015.

Dunn, Elizabeth C. “Humanitarianism, Displacement, and the Politics of Nothing in Postwar Georgia.” *Slavic Review* 73, 2 (2014): 287–306. https://doi.org/10.5612/slavicreview.73.2.287.

Durham, Deborah. “Soliciting Gifts and Negotiating Agency: The Spirit of Asking in Botswana.” *The Journal of the Royal Anthropological Institute* 1, no. 1 (1995): 111–28. https://doi.org/10.2307/3034231.

Eastmond, M. “Stories as Lived Experience: Narratives in Forced Migration Research“. *Journal of Refugee Studies* 20 (2) (2007): 248–64. https://doi.org/10.1093/jrs/fem007.

Easton-Calabria, Evan. “Warriors of Self-Reliance: The Instrumentalization of Afghan Refugees in Pakistan.” *Journal of Refugee Studies* 33, no. 1 (2020): 143–66. https://doi.org/10.1093/jrs/fez062.

Easton-Calabria, Evan, and Naohiko Omata. “Panacea for the Refugee Crisis? Rethinking the Promotion of ‘Self-Reliance’ for Refugees.” *Third World Quarterly* 39, no. 8 (2018): 1458–1474. https://doi.org/10.1080/01436597.2018.1458301.

Easton-Calabria, Evan, and Maurice Herson. “In Praise of Dependencies: Dispersed Dependencies and Displacement.” *Disasters* 44, no. 1 (2020): 44–62. https://doi.org/10.1111/disa.12366.

Eckert, Julia. “Introduction: Subjects of Citizenship.” *Citizenship Studies* 15, 3–4 (2011): 309–17. https://doi.org/10.1080/13621025.2011.565153.

Edgerton, Robert B. *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded.* Berkeley: University of California Press, 1967.

Englund, Harri. *Prisoners of Freedom: Human Rights and the African Poor.* Berkeley: University of California Press, 2006.

Epstein, Andrew I. “Education of Refugees and the Spatial Politics of Childhood Vulnerability.” *Childhood in Africa. An Interdisciplinary Journal* 1, no. 2 (2010): 16–25.

Eyben, Rosalind. “Labelling People for Aid.” In *The Power of Labelling: How People are Categorized and Why it Matters*, edited by Joy Moncrieffe and Rosalind Eyben, 33–47. London: Earthscan, 2007.

Fassin, Didier. “Quand le corps fait loi. La raison humanitaire dans les procédures de régularisation des étrangers.” *Sciences sociales et santé* 19 (2001): 5–34. https://doi.org/10.3406/sosan.2001.1533.

Fassin, Didier. “Compassion and Repression: The Moral Economy of Immigration Policies in France.” *Cultural Anthropology* 20, no. 3 (2005): 362–87. https://doi.org/10.1525/can.2005.20.3.362.

Fassin, Didier. *Humanitarian Reason: A Moral History of the Present.* Berkeley: University of California Press, 2012.

Fassin, Didier, and Estelle D’Halluin. “The Truth from the Body: Medical Certificates as Ultimate Evidence for Asylum Seekers.” *American Anthropologist* 107, no. 4 (2005): 597–608. https://doi.org/10.1525/aa.2005.107.4.597.

Fassin, Didier, and Richard Rechtman. *The Empire of Trauma: An Inquiry Into the Condition of Victimhood.* Princeton: Princeton University Press, 2009.

Feldman, Ilana, and Miriam Ticktin. *In the Name of Humanity: The Government of Threat and Care.* Durham: Duke University Press, 2010.

Feldman, Ilana. “The Challenge of Categories: UNRWA and the Definition of a ‘Palestine Refugee’.” *Journal of Refugee Studies* 25, no. 3 (2012): 387–406. https://doi.org/10.1093/jrs/fes004.

Ferguson, James. *The Anti-Politics Machine: “Development”, Depoliticization, and Bureaucratic Power in Lesotho.* Minneapolis: University of Minnesota Press, 1994.

Ferguson, James. “Declarations of Dependence: Labour, Personhood, and Welfare in Southern Africa.” *Journal of the Royal Anthropological Institute* 19, no. 2 (2013): 223–42. https://doi.org/10.1111/1467-9655.12023.

Ferguson, James. *Give a Man a Fish: Reflections on the New Politics of Distribution.* Durham: Duke University Press, 2015.

Fineman, Martha Albertson. “The Vulnerable Subject: Anchoring Equality in the Human Condition.” *SSRN Scholarly Paper* ID 1131407. Rochester, NY: Social Science Research Network, 2008. https://papers.ssrn.com/abstract=1131407.

Fortes, Meyer, and Edward E. Evans-Pritchard. *African Political Systems.* London: Routledge, 1987.

Frank, Gelya. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America.* Berkeley: University of California Press, 2000.

Friedner, Michele Ilana. *Valuing Deaf Worlds in Urban India.* New Brunswick: Rutgers University Press, 2015.

Geurts, Kathryn. *Culture and the Senses: Bodily Ways of Knowing in an African Community*. Berkeley: University of California Press, 2003.

Gill, Michael C., and Cathy J. Schlund-Vials. *Disability, Human Rights and the Limits of Humanitarianism.* London; New York: Routledge, 2016. http://www.tandfebooks.com/isbn/9781315577401.

Ginsburg, Faye, and Rayna Rapp. “Disability Worlds.” *Annual Review of Anthropology* 42, no. 1 (2013): 53–68. https://doi.org/10.1146/annurev-anthro-092412-155502.

Givetash, Linda. “How Uganda’s Economy Has Received a Boost from Hosting Refugees.” *Quartz* (blog). 24th of July 2018. https://qz.com/548576/how-ugandas-economy-has-received-a-boost-from-hosting-refugees/.

Glasman, Joël. "Seeing Like a Refugee Agency: A Short History of UNHCR Classifications in Central Africa (1961–2015)." *Journal of Refugee Studies* 30, no. 2 (2015): 337–362. https://doi.org/10.1093/jrs/few044.

Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon & Schuster, 2009.

Government of Uganda (GoU). "Second National Development Plan (NDPII) 2015/16–219/20", 2015. http://npa.ug/wp-content/uploads/NDPII-Final.pdf.

Government of Uganda (GoU), UNHCR, WFP. "Uganda Joint Assessment Mission 2014", 2014. https://www.unhcr.org/sites/default/files/legacy-pdf/54d3762f0.pdf

Grech, Shaun. "Disability, Poverty and Development: Critical Reflections on the Majority World Debate." *Disability & Society* 24, no. 6 (2009): 771–84. https://doi.org/10.1080/09687590903160266.

Grech, Shaun, and Karen Soldatic. *Disability in the Global South: The Critical Handbook.* Berlin: Springer, 2016.

Green, Maia. "Calculating Compassion: Accounting for Categorical Practices in International Development." In *Adventures in Aidland. The Anthropology of Professionals in International Development* (Studies in Public and Applied Anthropology 6), edited by David Mosse, 33–56. Oxford: Berghan Books, 2011.

Grischow, Jeff D. "'I Nearly Lost my Work': Chance Encounters, Legal Empowerment and the Struggle for Disability Rights in Ghana." *Disability & Society* 30, no. 1 (2015): 101–13. https://doi.org/10.1080/09687599.2014.982786.

Groce, Nora Ellen. *Everyone Here Spoke Sign Language.* Cambridge: Harvard University Press, 2009.

Gutierrez Garza, Ana Paola. *Care for Sale: An Ethnography of Latin American Domestic and Sex Workers in London.* Oxford: Oxford University Press, 2019.

Gupte, Jaideep, and Lyla Mehta. "Disjunctures in Labelling Refugees and Oustees." In *The Power of Labelling: How People are Categorized and Why it Matters*, edited by Joy Moncrieffe and Rosalind Eyben, 64–79. London: Earthscan, 2007.

Handicap International (HI). "Disability in Humanitarian Context. Views from Affected People and Field Organisations. Humanitarian International Foundation", 2015. https://handicap-international.ch/sites/ch/files/documents/files/disability-humanitarian-context.pdf.

Harrell-Bond, Barbara. *Imposing Aid: Emergency Assistance to Refugees.* Oxford: Oxford University Press, 1986.

Harrell-Bond, Barbara. "Can Humanitarian Work with Refugees be Humane?" *Human Rights Quarterly* 24, no. 1 (2002): 51–85. Jstor.

Harrell-Bond, Barbara, Eftihia Voutira, and Mark Leopold. "Counting the Refugees: Gifts, Givers, Patrons and Clients." *Journal of Refugee Studies* 5, no. 3–4 (1992): 205–25. https://doi.org/10.1093/jrs/5.3-4.205.

Hartblay, Cassandra. "Good Ramps, Bad Ramps: Centralized Design Standards and Disability Access in Urban Russian Infrastructure." *American Ethnologist* 44, no. 1 (2017): 9–22. https://doi.org/10.1111/amet.12422.

Heijmans, Annelies. *Vulnerability: A Matter of Perception.* Brighton: Benfield Greig Hazard Research Centre, 2001.

Heller, Tamar, and Sarah K. Parker Harris. *Disability Through the Life Course.* Thousand Oaks: SAGE Publications Inc., 2011.

Hollander, Theo, and Bani Gill. "Every Day the War Continues in My Body: Examining the Marked Body in Postconflict Northern Uganda." *International Journal of Transitional Justice* 8, no. 2 (2014): 217–234. https://doi.org/10.1093/ijtj/iju007.

Horden, Peregrine and Richard Smith, eds. *The Locus of Care: Families, Communities, Institutions, and the Provision of Welfare since Antiquity*. London: Routledge, 1997.

Hovil, Lucy. "Self-settled Refugees in Uganda: An Alternative Approach to Displacement?" *Journal of Refugee Studies* 20, no. 4 (2007): 599–620. https://doi.org/10.1093/jrs/fem035.

Hyndman, Jennifer. *Managing Displacement: Refugees and the Politics of Humanitarianism.* Minnesota: University of Minnesota Press, 2000.

Iazzolino, Gianluca. "Power Geometries of Encampment. The Reproduction of Domination and Marginality among Somali Refugees in Kakuma." *Geoforum* 110 (2020): 25–34. https://doi.org/10.1016/j.geoforum.2020.01.010.

Ilcan Susan, Marcia Oliver, and Laura Connoy. "Humanitarian Assistance and the Politics of Self-Reliance: Uganda's Nakivale Refugee Settlement", 2015. CIGI Papers 86. https://www.cigionline.org/publications/humanitarian-assistance-and-politics-self-reliance-ugandas-nakivale-refugee-settlement/.

Ingstad, Benedicte. *Community-Based Rehabilitation in Botswana: The Myth of the Hidden Disabled.* Lewiston: Edwin Mellen Press, 1997.

Ingstad, Benedicte, and Susan Reynolds Whyte. *Disability and Culture.* Berkeley: University of California Press, 1995.

Ingstad, Benedicte, and Susan Reynolds Whyte. *Disability in Local and Global Worlds.* Berkeley: University of California Press, 2007.

Inhetveen, Katharina. *Die politische Ordnung des Flüchtlingslagers: Akteure, Macht, Organisation: Eine Ethnographie im Südlichen Afrika.* Bielefeld: transcript Verlag, 2010.

International Migration Organization (IOM) Uganda. "Resettlement Operations". Accessed November 11, 2018. https://uganda.iom.int/resettlement-operations.

Jansen, Bram J. *Kakuma Refugee Camp: Humanitarian Urbanism in Kenya's Accidental City.* London: Zed Books, 2018.

Jansen, Stef, and Staffan Löfving. "Introduction: Movement, Violence, and the Making of Home." *Focaal*, no. 49 (2007): 3–14. https://doi.org/10.3167/foc.2007.490102.

Jacobsen, Karen. *The Economic Life of Refugees.* Boulder: Kumarian Press, 2005.

Jaji, Rose. "Social Technology and Refugee Encampment in Kenya." *Journal of Refugee Studies* 25, no. 2 (2012): 221–38. https://doi.org/10.1093/jrs/fer046.

Janmyr, Maja, and Lama Mourad. "Modes of Ordering: Labelling, Classification and Categorization in Lebanon's Refugee Response." *Journal of Refugee Studies* 31, no. 4 (2018): 544–565. https://doi.org/10.1093/jrs/fex042.

Jaspars, Susanne, and Jeremy Shoham. "Targeting the Vulnerable: A Review of the Necessity and Feasibility of Targeting Vulnerable Households." *Disasters* 23, no. 4 (1999): 359–72. https://doi.org/10.1111/1467-7717.00125.

Kaiser, Tania. "Sudanese Refugees in Uganda and Kenya." In *Protracted Refugee Situations: Political, Human Rights and Security Implications*, edited by Gil Loescher, James Milner, Edward Newman, and Gary Troeller, 248–276. New York: United Nations University Press, 2008.

Karanja, Michael. "Disability in Contexts of Displacement." *Disability Studies Quarterly* 29, no. 4 (2009). http://dsq-sds.org/article/view/969.

Kelly, Gabrielle. "Patient Agency and Contested Notions of Disability in Social Assistance Applications in South Africa." Social Science & Medicine 175 (2017): 109–116. https://doi.org/10.1016/j.socscimed.2017.01.013.

Kett, Maria, and John Twigg. "Disability and Disasters: Towards an Inclusive Approach." In *World Disaster Report 2007*. International Federation of the Red Cross and the Red Crescent. http://discovery.ucl.ac.uk/122164/.

Kett, Maria, and Mark van Ommeren. "Disability, Conflict, and Emergencies." *The Lancet* 374, no. 9704 (2009): 1801–1803. https://doi.org/10.1016/S0140-6736(09)62024-9.

Kett, Maria, and Jean-Francois Trani. "Vulnerability and Disability in Darfur." *Forced Migration Review* 35 (2010): 12–14.

Kibreab, Gaim. "The Myth of Dependency among Camp Refugees in Somalia 1979–1989." *Journal of Refugee Studies* 6, no. 4 (1993): 321–49. https://doi.org/10.1093/jrs/6.4.321.

Kim, Eunjung. "The Specter of Vulnerability and Disabled Bodies in Protest." In *Disability, Human Rights and the Limits of Humanitarianism*, edited by Michael Gill and Cathy J Schlund-Vials, 137–54. Farnham: Ashgate Publishing, 2014.

Kleinman, Arthur, Veena Das, Margaret Lock, and Margaret M. Lock. *Social Suffering.* Berkeley: University of California Press, 1997.

Kohrman, Matthew. "Why Am I Not Disabled? Making State Subjects, Making Statistics in Post-Mao China." *Medical Anthropology Quarterly* 17, no. 1 (2003): 5–24. https://doi.org/10.1525/maq.2003.17.1.5.

Kohrman, Matthew. *Bodies of Difference: Experiences of Disability and Institutional Advocacy in the Making of Modern China.* Berkeley: University of California Press, 2005.

Kopf, Dan. "Think you know how the poor would spend the money you give them?", 2016. World Economic Forum (WEF). https://www.weforum.org/agenda/2016/12/giving-money-to-the-poor-heres-what-they-really-spend-it-on?utm_content=bufferbc7d0&utm_medium=social&utm_source=twitter.com&utm_campaign=buffer.

Krause, Ulrike. "Humanitären Flüchtlingsschutz Entwicklungsorientiert Gestalten?" Netzwerk Flüchtlingsforschung (blog). 22nd August 2016. http://fluechtlingsforschung.net/humanitaren-fluchtlingsschutz-entwicklungsorientiert-gestalten/.

Lauterbach, Karen. "Religion and Displacement in Africa." *Religion and Theology* 21, no. 3 (2014): 290–308. https://doi.org/10.1163/15743012-02103004.

Lee, Richard B. *The Dobe Ju/'Hoansi.* Boston: Cengage Learning, 2012.

Livingston, Julie. *Debility and the Moral Imagination in Botswana.* Bloomington: Indiana University Press, 2005.

Lwanda, John. *Politics, Culture and Medicine in Malawi.* Oxford: African Books Collective, 2000.

Mackelprang, Romel W., and Richard O. Salsgiver. *Disability: A Diversity Model Approach in Human Service Practice* (3rd revised edition). Oxford: Oxford University Press, 2016.

Malkki, Lisa H. "National Geographic: The Rooting of Peoples and the Territorialization of National Identity among Scholars and Refugees." *Cultural Anthropology* 7, no. 1 (1992): 24–22. Jstor.

Malkki, Lisa H. "Refugees and Exile: From 'Refugee Studies' to the National Order of Things." *Annual Review of Anthropology* 24, 1 (1995): 495–523. Jstor.

Malkki, Lisa H. "Speechless Emissaries: Refugees, Humanitarianism, and Dehistoricization." *Cultural Anthropology* 11, no. 3 (1996): 377–404. https://doi.org/10.1525/can.1996.11.3.02a00050.

Malkki, Lisa H. *Purity and Exile: Violence, Memory, and National Cosmology among Hutu Refugees in Tanzania.* Chicago: University of Chicago Press, 2012.

Malkki, Lisa H. *The Need to Help: The Domestic Arts of International Humanitarianism.* Durham: Duke University Press, 2015.

Mamdani, Mahmood. *When Victims Become Killers: Colonialism, Nativism, and the Genocide in Rwanda.* Princeton: Princeton University Press, 2002.

Manderson, Lenore and Ellen Block. "Relatedness and care in Southern Africa and beyond." *Social Dynamics* 42, no. 2 (2016): 205–217. https://doi.org/10.1080/02533952.2016.1218139.

Matsiko, Haggai. "Whose Mess is Kyangwali Camp?", *The Independent*, 13th September 2013. https://www.independent.co.ug/whose-mess-kyangwali-camp/

Mazunda, Henry. "Burundi refugees with disabilities call on camp officials to better meet their needs", 2017. Help Age International. News and Views. http://www.helpage

.org/blogs/henry-mazunda-28538/burundi-refugees-with-disabilities-call-on-camp-officials-to-better-meet-their-needs-1058/.

McKay, Ramah. “Afterlives: Humanitarian Histories and Critical Subjects in Mozambique.” *Cultural Anthropology* 27, 2 (2012): 286–309. https://doi.org/10.1111/j.1548-1360.2012.01144.x.

McKay, Ramah. *Medicine in the Meantime: The Work of Care in Mozambique.* Durham: Duke University Press, 2018.

McKearney, Patrick, and Megha Amrith. “Care.” In *The Open Encyclopedia of Anthropology*, edited by Felix Stein. Facsimile of the first edition in The Cambridge Encyclopedia of Anthropology, 2023. http://doi.org/10.29164/21care.

Meekosha, Helen. “Decolonising Disability: Thinking and Acting Globally.” *Disability & Society* 26, 6 (2011): 667–82. https://doi.org/10.1080/09687599.2011.602860.

Meinert, Lotte, Hanne O. Morgensen, and Jenipher Twebaze. “Test for Life Chances: CD4 Miracles and Obstacles in Uganda.” *Anthropology & Medicine* 16, 2 (2009): 195–209.

Merriam-Webster. “Benefaction”. Accesed November 11, 2018. https://www.merriam-webster.com/dictionary/benefaction.

Meth, Charles. “Ideology and Social Policy: ‘Hand-outs’ and the Spectre of ‘Dependency’.” *Transformation: Critical Perspectives on Southern Africa* 56 (2004): 1–30. Project MUSE.

Meyer, Sarah. “The ‘Refugee Aid and Development’ Approach in Uganda: Empowerment and Self-Reliance of Refugees in Practice.” UNHCR Research Paper No. 131, 2006. http://www.unhcr.org/research/working/4538eb172/refugee-aid-development-approach-uganda-empowerment-self-reliance-refugees.html.

Miers, Suzanne, and Igor Kopytoff. *Slavery in Africa: Historical and Anthropological Perspectives.* Madison: University of Wisconsin Press, 1979.

Mikuš, Marek. “Between Recognition and Redistribution: Disability, (Human) Rights, and Struggles over Welfare in Serbia.” *Journal of the Royal Anthropological Institute* 24, no. 2 (2018) *Disability & Society* 26, no. 5 (2011a): 521–35. https://doi.org/10.1080/09687599.2011.589188.

Mirza, Mansha. “Disability and Cross-Border Mobility: Comparing Resettlement Experiences of Cambodian and Somali Refugees with Disabilities.” *Disability & Society* 26, no. 5 (2011a): 521–535. https://doi.org/10.1080/09687599.2011.589188.

Mirza, Mansha. “Disability and Humanitarianism in Refugee Camps: The Case for a Travelling Supranational Disability Praxis.” *Third World Quarterly* 32, no. 8 (2011b): 1527–36. https://doi.org/10.1080/01436597.2011.604524.

Mirza, Mansha. “Disability-Inclusive Healthcare in Humanitarian Camps: Pushing the Boundaries of Disability Studies and Global Health.” *Disability and the Global South* 2, no. 1 (2015): 479–500.

Mitchell, David, and Valerie Karr. *Crises, Conflict and Disability: Ensuring Equality* (Routledge Advances in Disability Studies). London: Routledge, 2014.

Müller, Tanja R. "The Long Shadow of Band Aid Humanitarianism: Revisiting the Dynamics between Famine and Celebrity." *Third World Quarterly* 34, no. 3 (2013): 470–84. https://doi.org/10.1080/01436597.2013.785342.

Murphy, Robert F. *The Body Silent.* New York: Norton, 2001.

Muyinda, Herbert, "Limbs and Lives - Disability, Violent Conflict and Embodied Sociality in Northern Uganda." PhD diss., University of Copenhagen, 2008.

Muyinda, Herbert, and Susan Reynolds Whyte. "Displacement, Mobility and Poverty in Northern Uganda." In *Disability and Poverty. A Global Challenge,* edited by Arne H.Eide and Benedict Ingstad, 119–136, Bristol: The Policy Press, 2011.

Nabenyo, Emmanuel Ekai. "Freeing Refugees From the Limbo of Donor Dependency. An Analysis of Kenya's Refugees Bill, 2016." Master's thesis, University of Dar es Salaam, 2019.

Nagujja, Yusrah. *Rehabilitation and Integration of Refugee and Other Displaced Children with Disabilities in Uganda.* Unpublished report: Refugee Law Project, Makerere University, 2013.

Nagujja, Yusrah, "Social Support for Refugee Children on Antiretroviral Therapy in Kyaka II Refugee Settlement, Kyegegwa District, Uganda." PhD diss., Makerere University, 2014.

Nakamura, Karen. *Deaf in Japan: Signing and the Politics of Identity.* Ithaca: Cornell University Press, 2006.

Nguyen, Vinh-Kim. "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship". In *Global Assemblages, Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier, 124–144. Hoboken: Blackwell Publishing, 2008.

Nguyen, Vinh-Kim. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham: Duke University Press, 2010.

Njelesani, Janet, Shaun Cleaver and Myroslava Tatryn. "Practical Strategies to Meet the Rights of Persons with Disabilities in Disaster Management Initiatives." In *Crises, Conflict and Disability. Ensuring Equality* (Routledge Advances in Disability Studies), edited by David Mitchell and Valerie Karr, 84–89. London: Routledge, 2014.

Norris, Karen. "Livelihood Security Among Refugees in Uganda: Opportunities, Obstacles, and Physical Security Implications." Independent Study Project (ISP) Collection, 2013. http://digitalcollections.sit.edu/isp_collection/1686.

Nussbaum, Martha C. *Frontiers of Justice: Disability, Nationality, Species Membership.* Cambridge: Harvard University Press, 2009.

OCHA. "Democratic Republic of Congo. North Kivu. Situation Report No.17", 2012. https://reliefweb.int/sites/reliefweb.int/files/resources/North%20Kivu%20Situa tion%20Report%2017,%20OCHA%20-%20DRC.pdf.

O'Connor, Daniel, Philip Boyle, Suzan Ilcan, and Marcia Oliver. "Living with Insecurity: Food Security, Resilience, and the World Food Programme (WFP)." *Global Social Policy* 17, no. 1 (2017): 3–20. https://doi.org/10.1177/1468018116658776.

Oka, Rahul Chandrashekhar. “Coping with the Refugee Wait: The Role of Consumption, Normalcy, and Dignity in Refugee Lives at Kakuma Refugee Camp, Kenya.” *American Anthropologist* 116, no. 1 (2014): 23–37. https://doi.org/10.1111/aman.12076.

Okiror, Samuel. “Tensions in Uganda after Funding Delays Lead to Reduced Food Rations for Refugees.” *The Guardian,* 9th October 2017. https://www.theguardian.com/global-development/2017/oct/09/tensions-flare-as-food-rations-to-refugees-slashed-by-half-in-uganda.

Oliver, Michael. *The Politics of Disablement.* Critical Texts in Social Work and the Welfare State. London: Red Globe Press, 1990.

Omata, Naohiko, and Joseph Kaplan. “Refugee livelihoods in Kampala, Nakivale and Kyangwali Refugee Settlements. Patterns of Engagement with the Private Sector.” Working Paper 95. Refugee Studies Centre Working Paper Series. Refugee Studies Centre, University of Oxford, 2013.

Ong, Aihwa. *Flexible Citizenship: The Cultural Logics of Transnationality.* Durham: Duke University Press, 1999.

Oxford Dictionaries. “Livelihood.” Accessed June 14, 2018. https://en.oxforddictionaries.com/definition/us/livelihood.

Patton, Anna. “Is Uganda the Best Place to Be a Refugee?” *The Guardian,* 20th August 2016, Global Development Professionals Network section. https://www.theguardian.com/global-development-professionals-network/2016/aug/20/is-uganda-the-best-place-to-be-a-refugee.

Pearce, Emma. “Refugee and Displaced Persons with Disabilities – from ‘Forgotten’ to ‘Vulnerable’ to ‘Valuable’.” *Forced Migration Review* (25th Anniversary Collection). 2013. http://www.fmreview.org/sites/fmr/files/FMRdownloads/en/FMR%2025th%20anniversary%20full%20issue%20web.pdf.

Petryna, Adriana. “Biological Citizenship. The Science and Politics of Chernobyl-Exposed Populations.” In *A Reader in Medical Anthropology. Theoretical Trajectories, Emergent Realities*, edited by Byron J. Good, Michael M. J. Fischer, Sarah S. Willen, and Mary-Jo DelVecchio Good, 199–212. Hoboken: Wiley-Blackwell, 2010.

Petryna, Adriana. *Life Exposed: Biological Citizens after Chernobyl.* Princeton: Princeton University Press, 2013.

Phillips, Sarah D. *Disability and Mobile Citizenship in Postsocialist Ukraine.* Bloomington: Indiana University Press, 2011.

Pisani, Maria, and Shaun Grech. “Disability and Forced Migration: Critical Intersectionalities.” *Disability and the Global South* 2, no. 1 (2017): 421–441. http://repositoriocdpd.net:8080/handle/123456789/1505.

Ramsay, Georgina. “Avoiding Poison: Congolese Refugees Seeking Cosmological Continuity in Urban Asylum.” *Social Analysis* 60, no. 3 (2016): 112–28. https://doi.org/10.3167/sa.2016.600307.

Ramsay, Georgina. *Impossible Refuge: The Control and Constraint of Refugee Futures.* London: Routledge, 2017.

Rapp, Rayna, and Faye D. Ginsburg. "Enabling Disability: Rewriting Kinship, Reimagining Citizenship." *Public Culture* 13, no. 3 (2001): 533–56. https://doi.org/10.1215/08992363-13-3-533.

Rapp, Rayna. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America.* London: Psychology Press, 1999.

Refugees International (RI). "Displaced and Disabled", 2003. http://www.reliefweb.int/.

Reilly, Rachael. "Disabilities Among Refugees and Conflict-Affected Populations." Women's Refugee Commission (WRC), 2008. http://www.fmreview.org/fr/node/275?text_size=large-text.

Rieff, David. *A Bed for the Night: Humanitarianism in Crisis.* New York: Simon & Schuster, 2003.

Rose, Nikolas, and Carlos Novas. "Biological Citizenship". In *Global Assemblages, Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong, and Stephen J. Collier, 439–63. Hoboken: Wiley-Blackwell, 2008. https://doi.org/10.1002/9780470696569.ch23.

Sandvik, Kristin Bergtora. "Blurring Boundaries: Refugee Resettlement in Kampala - Between the Formal, the Informal, and the Illegal." *PoLAR: Political and Legal Anthropology Review* 34, no. 1 (2011): 11–32. https://doi.org/10.1111/j.1555-2934.2011.01136.x.

Sandvik, Kristin Bergtora, and Katja Lindskov Jacobsen. *UNHCR and the Struggle for Accountability: Technology, Law and Results-Based Management.* London: Routledge, 2016.

Scalettaris, Giulia. "Refugee Studies and the International Refugee Regime: a Reflection on a Desirable Separation." *Refugee Survey Quarterly* 26, no. 3 (2007): 36–50. https://doi.org/10.1093/rsq/hdi0241.

Scherz, China. *Having People, Having Heart: Charity, Sustainable Development, and Problems of Dependence in Central Uganda.* Chicago: University of Chicago Press, 2014.

Schmidt, Anna. "Camps Versus Settlements" *Forced Migration Online*, 10th March 2003. http://www.forcedmigration.org/research-resources/expert-guides/camps-versus-settlements/alldocuments.

Schuler, Maria-Theres. "Discomfort, Complaints, and Claims. Conducting Fieldwork with Refugees with Disabilities." *Medicine Anthropology Theory*, 29th March 2018, Dissertating section. http://www.medanthrotheory.org/read/10561/discomfort-complaints-claims.

Scott-Smith, Tom. "Beyond the Boxes." *American Ethnologist* 46, no. 4 (2019): 509–21. https://doi.org/10.1111/amet.12833.

Shakespeare, Tom. "The Social Model of Disability." In *The Disability Studies Reader*, edited by Lennard J. Davis, 2–197. London: Psychology Press, 2006.

Sharpe, Marina, and Salima Namusobya. "Refugee Status Determination and the Rights of Recognized Refugees under Uganda's Refugees Act 2006." *International Journal of Refugee Law* 24, no. 3 (2012): 561–78. https://doi.org/10.1093/ijrl/ees036.

Smith, Daniel Jordan. "Patronage, Per Diems and the 'Workshop Mentality': The Practice of Family Planning Programs in Southeastern Nigeria." *World Development* 31, no. 4 (2003): 703–15. https://doi.org/10.1016/S0305-750X(03)00006-8.

Smith, Daniel Jordan. "Contradictions in Nigeria's Fertility Transition: The Burdens and Benefits of Having People." *Population and Development Review* 30, no. 2 (2004): 221–38. https://doi.org/10.1111/j.1728-4457.2004.011_1.x.

Smith-Khan, Laura, Mary Crock, Ben Saul, and Ron McCallum. "To 'Promote, Protect and Ensure': Overcoming Obstacles to Identifying Disability in Forced Migration." *Journal of Refugee Studies* 28, no. 1 (2014): 38–68. https://doi.org/10.1093/jrs/feu020.

Stiker, Henri-Jacques. *A History of Disability.* Ann Arbor: University of Michigan Press, 1999.

Stone, Deborah. *The Disabled State.* Philadelphia: Temple University Press, 1986.

Svedberg, Erik. "Refugee Self-Reliance in Nakivale Refugee Settlement, Uganda." Independent Study Project (ISP) Collection, 2014. https://digitalcollections.sit.edu/isp_collection/1778.

Swidler, Ann. "Dialectics of Patronage: Logics of Accountability at the African AIDS-NGO Interface". In *Philanthropic Projections: Sending Institutional Logics Abroad*, edited by Steven Heydemann and David Hammack, 92–220. Bloomington: Indiana University Press, 2009.

The Sphere Project. "Humanitarian Charter and Minimum Standards in Humanitarian Aid", 2011. https://www.spherestandards.org/wp-content/uploads/2018/06/Sphere_Handbook_2011_English.pdf.

Thelen, Tatjana. "Care as Social Organisation: Creating, Maintaining and dissolving significant relations." *Anthropological Theory*, 15, no. 4 (2015): 497–515. https://doi.org/10.1177/1463499615600893.

Thomas, Carol. "Disability Theory : Key Ideas, Issues and Thinkers." In *Disability Studies Today*, edited by Colin Barnes, Len Barton, and Mike Oliver, 38–57. Cambridge: Polity Press, 2002.

Thompson, Caroline. "South Sudan Crisis Strains Uganda's Exemplary Refugee Welcome." *Huffington Post,* 4th November 2016, WorldPost section. http://www.huffingtonpost.com/entry/south-sudan-crisis-uganda-refugees_us_581b9a93e4b0aac624831603.

Thomson, Marnie Jane. "Black Boxes of Bureaucracy: Transparency and Opacity in the Resettlement Process of Congolese Refugees." *PoLAR: Political and Legal Anthropology Review* 35, no. 2 (2012): 186–205. https://doi.org/10.1111/j.1555-2934.2012.01198.x.

Ticktin, Miriam. "Where Ethics and Politics Meet: The Violence of Humanitarianism in France." *American Ethnologist* 33, no. 1 (2006): 33–49. Jstor.

Ticktin, Miriam. *Casualties of Care: Immigration and the Politics of Humanitarianism in France.* Berkeley: University of California Press, 2011a.

Ticktin, Miriam. "The Gendered Human of Humanitarianism: Medicalising and Politicising Sexual Violence." *Gender & History* 23, no. 2 (2011b): 250–65. https://doi.org/10.1111/j.1468-0424.2011.01637.x.

Ticktin, Miriam. "Transnational Humanitarianism." *Annual Review of Anthropology* 43, no. 1 (2014): 273–89. https://doi.org/10.1146/annurev-anthro-102313-030403.

Trapp, Micah M. "You-Will-Kill-Me-Beans: Taste and the Politics of Necessity in Humanitarian Aid." *Cultural Anthropology* 31, no. 3 (2016): 412–37. https://doi.org/10.14506/ca31.3.08.

Turner, Simon. *Politics of Innocence: Hutu Identity, Conflict, and Camp Life.* Oxford: Berghahn Books, 2010.

Turner, Simon. "What Is a Refugee Camp? Explorations of the Limits and Effects of the Camp." *Journal of Refugee Studies* 29, no. 2 (2016): 139–48. https://doi.org/10.1093/jrs/fev024.

UNHCR. "The Community Services Function in UNHCR. An Independent Evaluation". Evaluation and Policy Analysis Unit, 2003. http://www.unhcr.org/research/evalreports/3e2d233ba/community-services-function-unhcr-independent-evaluation.html.

UNHCR. "Handbook for Emergencies", 2007. https://www.refworld.org/pdfid/46a9e29a2.pdf.

UNHCR. "A Community-Based Approach in UNHCR Operations", 2008. http://www.unhcr.org/publications/legal/47ed0e212/community-based-approach-unhcr-operations.html.

UNHCR. "Conclusion on Refugees with Disabilities and Other Persons with Disabilities Protected and Assisted by UNHCR", 2010. http://www.unhcr.org/excom/exconc/4cbeb1a99/conclusion-refugees-disabilities-other-persons-disabilities-protected-assisted.html.

UNHCR. "UNHCR Resettlement Handbook", 2011a. http://www.unhcr.org/46f7c0ee2.pdf.

UNHCR. "Working with Persons with Disabilities in Forced Displacement", 2011b. http://www.unhcr.org/publications/manuals/4ec3c81c9/working-persons-disabilities-forced-displacement.html.

UNHCR. "Emergency Response for the Situation in the Eastern Democratic Republic of Congo". Donor Relations and Resource Mobilization Service, 2013. http://www.unhcr.org/5233253f9.pdf.

UNHCR. "UNHCR shocked and saddened at drowning of scores of Congolese refugees in Lake Albert, 2014. http://www.unhcr.org/news/latest/2014/3/53300d8a9/unhcr-shocked-saddened-drowning-scores-congolese-refugees-lake-albert.html.

UNHCR. "Charter on Inclusion of Persons with Disabilities in Humanitarian Action", 2016a. http://humanitariandisabilitycharter.org.

UNHCR. "Safeguarding Individuals", 2016b. http://www.unhcr.org/safeguarding-individuals.html.

UNHCR. "Global Trends: Forced Displacement in 2017", 2017. http://www.unhcr.org/5b27be547.pdf.

UNHCR. "Congolese Refugees, A Protracted Situation." Accessed November 11, 2018. http://www.unhcr.org/558c0e039.pdf.

United Nations (UN). "Transforming our World: The 2030 Agenda for Sustainable Development", 2015. https://sustainabledevelopment.un.org/post2015/transformingourworld.

United Nations Office for the Coordination of Humanitarian Affairs (OCHA). "About OCHA DRC", 2017. http://www.unocha.org/democratic-republic-congo-drc/about-ocha-drc.

Urech, Fabian. "Flüchtlingspolitik in Uganda: 'Ein Modell für die Welt'". Neue Zürcher Zeitung, 25th April 2017, International section. https://www.nzz.ch/international/fluechtlingspolitik-in-uganda-ein-modell-fuer-die-welt-ld.154177.

Vansina, Jan. *Paths in the Rainforests: Toward a History of Political Tradition in Equatorial Africa.* Madison: University of Wisconsin Press, 1990.

Voutira, Eftihia, and Barbara E. Harrell-Bond. "In Search of the Locus of Trust: The SocialWorld of the Refugee Camp." In *Mistrusting* Refugees, edited by Valentine E. Daniel and John Chr. Knudsen. Berkeley: University of California Press, 1995.

Waal, Alexander De. *Famine Crimes: Politics & the Disaster Relief Industry in Africa.* Melton: James Currey, 1997.

Werker, Eric. "Refugee Camp Economies." *Journal of Refugee Studies* 20, no. 3 (2007): 461–80. https://doi.org/10.1093/jrs/fem001.

Women's Refugee Commission (WRC). "Disability Inclusion. Translating Policy into Practice in Humanitarian Action", 2014. https://www.womensrefugeecommission.org/disabilities/disability-inclusion.

Women's Refugee Commission (WRC). "'The Woman Can Decide for Herself': The Intersection of Sexual and Reproductive Health and Disability for Refugees in Kakuma Refugee Camp, Kenya", 2015a. https://www.womensrefugeecommission.org/srh-2016/resources/1084-srh-disabilities-uganda-2014.

Women's Refugee Commission (WRC). "'I See that it is Possible': Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings", 2015b. https://www.womensrefugeecommission.org/resources/document/945-building-capacity-for-disability-inclusion-in-gender-based-violence-gbv-programming-in-humanitarian-settings-overview.

Women's Refugee Commission (WRC). "'Working to Improve our own Futures': Inclusion of Women and Girls with Disabilities in Humanitarian Action", 2016.

https://www.womensrefugeecommission.org/blog/2451-working-to-improve-our-own-futures-strengthening-networks-of-women-with-disabilities-in-humanitarian-action.

WFP. "Assessment of the Feasibility of Cash Transfer in Selected Refugee Settlements in Uganda: Koboko, Kyangwali, Kyaka II and Rwamwanja", Analysis, Monitoring and Evaluation (AME) Unit, 2015. https://data2.unhcr.org/en/documents/download/64138.

WFP. "Standard Project Report 2016", 2016a. https://docs.wfp.org/api/documents/f720635254c94747a25e0886a0bc0ad9/download/.

WFP. "Funding and Donors", 2016b. Accessed March 24, 2018. http://www1.wfp.org/funding-and-donors.

WFP, UNHCR, and OPM. "Uganda Joint Assessment Mission 2014", 2014. https://documents.wfp.org/stellent/groups/public/documents/ena/wfp269958.pdf?_ga=2.88907037.729385583.1542017425-1458718335.1524656443.

Whyte, Susan Reynolds. "Writing Knowledge and Acknowledgement: Possibilities in Medical Research." In *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa*, edited by Wenzel Geissler and Catherine Molyneux. Oxford: Berghahn Books, 2011.

Whyte, Susan Reynolds. "Epilogue." In *Dealing with Uncertainty in Contemporary African Lives*, edited by Liv Haram and C. Bawa Yamba, 213–216, Uppsala: Nordiska Afrikainstitutet, 2014.

Whyte, Susan Reynolds. "In the long run. Ugandans living with disability". *Current Anthropology* 61, no. 21 (2020): 132–140. https://doi.org/10.1086/704925.

Whyte, Susan Reynolds, ed., Godfrey Etyang, Phoebe Kajubi, David Kyaddondo, Lotte Meinert, Hanne Morgensen, Jenifer Twebaze, and Michael A. Whyte. *Second Chances: Surviving AIDS in Uganda.* Durham: Duke University Press, 2014.

Whyte, Susan Reynolds, and Herbert Muyinda. "Wheels and New Legs: Mobilization in Uganda." In *Disability in Local and Global Worlds*, edited by Benedicte Ingstad and Susan Reynolds Whyte, 287–310. Berkeley: University of California Press, 2007.

Whyte, Susan Reynolds, and Godfrey Etyang Siu. "Contingency: Interpersonal and Historical Dependencies in HIV Care." In *Ethnographies of Uncertainty in Africa.* (Anthropology, Change and Development), edited by Elizabeth Cooper and David Pratten, 19–35. London: Palgrave Macmillan, 2015. https://doi.org/10.1057/9781137350831_2.

Wülser, Patrik. "'Refugees Welcome' – Uganda Schafft Das." Schweizer Radio und Fernsehen (SRF). 28th September 2016. https://www.srf.ch/news/international/refugees-welcome-uganda-schafft-das.

Yeo, Rebecca, and Karen Moore. "Including Disabled People in Poverty Reduction Work: 'Nothing About Us, Without Us'." *World Development, Chronic Poverty and Development Policy*, 31, no. 3 (2003): 571–90. https://doi.org/10.1016/S0305-750X(02)00218-8.

Zelizer, Viviana. *The Purchase of Intimacy.* Princeton: Princeton University Press, 2009.

Zetter, Roger. “Labelling Refugees: Forming and Transforming a Bureaucratic Identity.” *Journal of Refugee Studies* 4, no. 1 (1991): 39–62. https://doi.org/10.1093/jrs/4.1.39.

Zetter, Roger. “More Labels, Fewer Refugees: Remaking the Refugee Label in an Era of Globalization.” *Journal of Refugee Studies* 20, no. 2 (2007): 172–92. https://doi.org/10.1093/jrs/fem011.

Zoanni, Tyler. “The Possibilities of Failure: Personhood and Cognitive Disability in Urban Uganda.” *The Cambridge Journal of Anthropology* 36, no. 1 (2018): 61–79. https://doi.org/10.3167/cja.2018.360105.

Index

At a time when rights are increasingly placed on the humanitarian agenda, this book provides a unique ethnographic account of the dynamics of aid to disabled people in a Ugandan refugee camp. By unraveling the complexities of social, material and institutional interdependencies, the author invites us to rethink conventional notions of dependence and vulnerability. Exploring issues of personhood as they relate to the exchange of material goods and care, the book offers a thought-provoking perspective on the seemingly promising shift towards a rights-based approach. A compelling read for anyone seeking to reshape the humanitarian agenda.

Maria-Theres Schuler, Ph.D. (2018) in Social Anthropology at the University of Zürich, currently writes as a journalist on global inequality, corporate responsibility and social movements with a focus on African countries.

ISSN 1574-6925
brill.com/agis

ISBN: 978-90-04-68301-3
9 789004 683013