

# **NEW ISSUES IN REFUGEE RESEARCH**

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## **Unmet needs and diminished opportunities: disability, displacement and humanitarian healthcare**

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## Introduction

Seven to ten percent of the world's 43.3 million forcibly displaced persons (UNHCR, 2010) are believed to be people with disabilities<sup>1</sup> (Women's Refugee Commission, 2008). The actual numbers might well be higher considering that situations which trigger population displacement not only place disabled persons at greater risk, but also create conditions that make more people disabled (Rockhold & McDonald, 2009).

People with disabilities have been historically neglected within humanitarian programs targeted at displaced populations, resulting in serious unmet needs and diminished opportunities for participation in various life domains (Kett & van Ommeren, 2009). To counter this oversight, scholarly publications and practice bulletins in the humanitarian field have only just released special theme issues on disability, indicating a growing disability consciousness among academics, practitioners, and advocates. Even the recently adopted United Nations Convention on the Rights of Persons with Disabilities specifically highlights the situation of disabled persons affected by humanitarian emergencies and calls for more inclusive and responsive humanitarian interventions (United Nations Commission on Human Rights 2007).

Addressing the needs of persons with disabilities is imperative for contemporary humanitarian interventions. It is important that this agenda be driven by systematic research and assessment. However serious information gaps exist and the evidence for effective response is weak pointing to the need for greater research on this topic (Simmons, 2010). The research study presented in this paper sought to address this information gap by investigating the health-related needs of displaced persons with disabilities and how these needs can be better addressed in the context of displacement camps.

The research focus on health and health-related concerns must not be taken to signify that disability issues fall strictly under the health domain. Disability is a complex social phenomenon and as such people with disabilities must be given due consideration across all sectors of humanitarian intervention. However, this research study chose to focus on the health sector for multiple reasons.

First, while disability issues are increasingly considered in certain humanitarian sectors such as education (Pinnock & Hodgkin, 2010), the health sector continues to lag. People with disabilities are frequently sidelined during health sector planning in displacement camps and encounter significant barriers to accessing basic health services, with availability of specialized health and rehabilitation services altogether lacking (Reilly, 2010; Shivji, 2010).

Access to appropriate health and rehabilitation services is an important human right enshrined in the Convention on the Rights of Persons with Disabilities (Stein, Stein, Weiss & Lang, 2009). This area has also been identified as warranting close attention in the EXCOM Conclusions on displaced persons with disabilities (Executive Committee, 2010). Unmet needs in this area can

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<sup>1</sup> The phrases "people/persons with disabilities" and "disabled people/persons" are used interchangeably in this report; a reflection of the lack of universally-accepted terminology. While some prefer people-first language, others, especially proponents of the social model of disability, prefer the term "disabled people".

hinder disabled people's participation in all other life domains thereby detrimentally affecting their overall well-being and quality of life.

Second, there is a widely-recognized dearth of research on disabled persons' access to appropriate healthcare and the responsiveness of health service systems to their needs. These areas have been identified as research priorities, warranting urgent attention especially in resource-constrained settings (Tomlinson et al., 2009; WHO, 2011). Very little is known about the typical organization of health services in displacement camps and the extent to which these services meet the health-related needs of persons with disabilities.

Much of the health-related research focusing on displacement camps has largely ignored disability issues, focusing instead on issues such as infectious and communicable diseases (e.g., UNAID, 2003; Roca, Charles, Jiminez & Nunez, 2011), reproductive health (e.g., Howard et al., 2011), nutrition interventions (e.g., Khatib, Samrah, Zghol, 2010), and mental health conditions (e.g., Mollica et al., 1993). Additionally, research has seldom considered the implications of population-based interventions and protocols for people with disabilities.

Thus there exists an information void regarding health considerations for persons with disabilities in displacement camps. With increased demand from donors to address health needs of displaced populations (Leaning, Spiegel & Crisp, 2010) it is imperative that existing information voids be filled in order to educate donors about existing service gaps for people with disabilities among displaced populations.

Finally, a focus on disability-related health needs is timely given recent reports of the changing health and demographic profile of displaced populations. There is growing evidence that health-care concerns of displaced populations, particularly those in protracted situations, are becoming more complex. While acute infectious diseases have long been a major area of concern, chronic non-infectious diseases are slowly on the rise as a result of longer life-expectancies among displaced populations as well as because significant numbers of displaced persons now originate from middle-income countries (Spiegel, Checchi, Colombo & Paik, 2010; UNRWA, 2010).

Many chronic conditions such as hypertension, diabetes, and cancer can lead to secondary functional impairments thereby increasing the numbers of persons with disabilities within these populations. Consequent to this development, health services in displacement camps, which have traditionally focused on preventive and curative responses to acute conditions, must evolve in order to address changing service needs. To inform the evolution of services systems, it is important to identify these needs and the adequacy of existing systems in responding to them.

In an attempt to shed light on this topic, this paper focuses on people with disabilities living in displacement camps, their access to health services, and existing and future strategies for addressing the health-related needs of this group. The research was guided by three questions: 1. How are health-related services typically organized in displacement camps; 2. What are the healthcare needs experienced by disabled people living in camps; 3. What are the barriers and facilitators affecting disabled people's access to needed healthcare services in camps?

## **Methods**

### *Conceptual Framework*

Conceptualizations of disability have evolved over time. Prior to the 1980s, disability was predominantly viewed as medical problem located within the individual (Craddock, 1996). To counter this ‘medical model’ of disability, British disability rights activists proposed a radically different view of disability as being socially constructed and resulting from environmental barriers (Oliver, 1996).

This alternative conceptualization of disability, known as the ‘social model’, called for a shift in approach from individual remediation and cure to addressing environmental barriers that limit opportunities for people with disabilities. Despite its increased influence since the 1980s, the social model has been criticized for ignoring disabled persons’ experiences of biological impairments that cannot be addressed solely by modifying their environment (Shakespeare & Watson, 2002).

The World Health Organization’s ‘International Classification of Functioning, Disability, and Health’ (ICF) attempts to merge biomedical and social/environmental conceptualizations of disability in the interest of serving disparate goals of environmental access and societal inclusion as well as individual treatment and rehabilitation (WHO, 2001). Within this framework disability is conceptualized as an umbrella term encompassing changes in an individual’s functioning and participation as the result of dynamic interplay between person-level and environmental factors.

Thus the framework incorporates a broad understanding of disability contingent on diverse lifestyles and environments and a wide range of physical, mental, sensory and chronic health conditions. The ICF framework is generally accepted by disability activists as more progressive than preceding WHO frameworks on disability (Hurst, 2003), although some contend that its focus on health obscures economic and social justice concerns of people with disabilities (Barnes & Mercer, 2010).

While the ICF was originally designed to be used for various purposes, including as an instrument for advancement of disability rights, its principal utility lies in providing a common language for understanding health-related states, outcomes, and determinants for people with disabilities (Ustun, Chatterji, Bickenbach, Kostanjsek, Schneider, 2003). Accordingly, the framework has been met with considerable global uptake within the health sector (Ustun et al., 2003; Bruyere, Van Looy & Peterson, 2005; Jelsma, 2009; Cerniauskaite et al., 2011). Since this paper focuses on health-related issues, the ICF framework was deemed most appropriate to guide the understanding of various aspects of health relevant to people with disabilities.

### *Methodological framework*

Given the scant research on health-related concerns of displaced persons with disabilities, the research questions addressed in this study represented an unexplored area. Therefore, a qualitative inquiry approach was used, which is well-suited to exploratory research questions. Since displacement settings are dynamic and evolving, the open-ended nature of qualitative

inquiry made it possible for the researcher to get into the field quickly and assess developing situations within a backdrop of constant change (Patton, 2002).

This study incorporated two methodological stages. The first stage involved five days of site-specific research in Dzaleka refugee camp in Malawi. Dzaleka camp is home to over 10,000 refugees most of them from the Democratic Republic of Congo, Rwanda, Burundi, and Somalia. The size of the camp, both in terms of geographical area and population made it an ideal setting to gain a quick yet comprehensive overview of 'typical' health-related services and needs within the context of displacement camps. In the second stage of research, key informant interviews were conducted over three months with humanitarian professionals with service experience in other displacement contexts.

Rapid Assessment Procedures (RAP), alternatively known as rapid reconnaissance or rapid ethnography (Patton, 2002), were used during the first stage of field research. The RAP framework was designed for resource-constrained research settings where the need for knowledge is immense but time and resources are limited (Afonja, 1992; Slim & Mitchell, 1992), and has been adapted for use with refugees and internally displaced persons (Weiss, Bolton & Shankar, 2000).

### *Study participants*

Study participants included key informants known for their work on disability and health in displacement settings. Efforts were made to recruit informants with and without disabilities, with and without personal experiences of displacement. Recruitment was restricted to individuals who were above 18, fluent and literate in English, and able to give informed consent.

Key informants at the field site were recruited through a snowball sampling strategy (Patton, 2002). A key point of contact in the camp introduced the researcher to potential key informant candidates. These individuals then suggested other potential key informants for the research. This snowball strategy evolved into a participatory enterprise as many of the initial field contacts made by the researcher were affiliated with the camp's Disabled Person's Association. These individuals were instrumental in helping the researcher draw a list of key informants who would be in strategic positions to shed light on the research topic.

Additional key informants from other sites were recruited remotely by email using a convenience sampling strategy (Patton, 2002). A pre-scripted email was posted to relevant listservs and other relevant contacts in the humanitarian field, and interested individuals were requested to contact the researcher to schedule interviews.

The sample size was originally set at 15 key informants, a number deemed appropriate to achieve data saturation (Patton, 2002) while presenting a feasible target given the limited scope of this study. However, recruitment was halted at 12 key informants; by this point data saturation was believed to have been achieved, with no new insights expected to be gained from additional interviews. Of the 12 key informants, half were female. Two respondents had personal experience with disability and displacement. Respondents' ages ranged from 25 to 64 years, although most respondents were under 40 years of age. Their experience with humanitarian work in displacement settings ranged from 10 months to 10 years and their areas of expertise included

social welfare, health, education, disability-specific services, and disability advocacy within the context of displacement. At the time of this research, three of the respondents were working for UN agencies, two were working for local NGOs, one worked for a Ministry of Health, and four were working for international NGOs of which two of the NGOs focused on disability-specific humanitarian and development work.

All respondents, with one exception, had experience working with conflict-displaced populations; one respondent had worked with populations displaced by both conflict and natural disaster. Between them, the respondents had worked in various geographical settings including: Kenya, Malawi, Sudan, Uganda, Democratic Republic of Congo, Yemen, Thailand-Burma, Palestine, Haiti, Sri Lanka, India, Pakistan, and the Philippines. All other details about respondents have been excluded in the interest of confidentiality.

### *Study procedures*

During the initial stage of field research, the researcher conducted community mapping exercises and guided tours, also referred to as participatory transects (Chambers, 1994), to develop an understanding of the general conditions and layout of the camp, the locations of key facilities and service centers. Non-participant observations were carried out in key settings that were open for public visitation such as meetings of the Disabled Person's Association, the waiting area of the camp health clinic, and the food distribution center.

The researcher also engaged in numerous informal conversations with disabled people and made numerous visits to the homes of camp residents with disabilities. These informal exchanges and observations offered a window into people's lived experiences (Patton, 2002) and also helped corroborate verbal reports from key informants (Adler & Adler, 1998).

Finally, semi-structured interviews were conducted with key informants. Interviews lasted for 30 to 60 minutes and inquired about the health-related needs of persons with disabilities the respondents had worked with, the overall availability of healthcare in the camp(s) where they had served, and the availability of specialized health and rehabilitation services for displaced people with disabilities services. Interviews were audio-recorded and transcribed verbatim.

In the second stage of the research, additional semi-structured interviews were conducted with key informants working in other sites. These interviews were similar in content to the ones described above, the only exception being they were conducted by phone. One respondent chose to contribute responses in writing owing to problems with phone reception and connectivity.

Lastly, extensive desk research and literature searches were conducted to corroborate and supplement data from field research and key informants. All study procedures were approved by the research ethics board at the researcher's university.

### *Data analysis*

Using step-by-step data coding procedures (Miles & Huberman, 1994), the researcher first read all transcripts and observation field notes while simultaneously documenting emerging insights and ideas. Next, transcripts and notes were re-examined line by line and codes were generated to categorize emerging themes. This process yielded an initial list of codes, which was refined and pared down to a smaller list of key themes during a second review of the data.

This was followed by more interpretative analysis where conceptual links were formulated to yield patterns and relationships between key themes. At this stage, the analysis yields were discussed with the researcher's disability activist colleagues, other experienced researchers (both with and without disabilities) in the fields of disability and rehabilitation and forced migration, and experts in humanitarian health and human rights. These discussions helped refine thematic patterns. To enhance credibility, the analysis procedure was subjected to an external audit (Lincoln & Guba, 1985). A peer reviewer was supplied with the final code list and segments of textual data selected across interview transcripts, and was instructed to use the list to code the data provided. This audit revealed a high rate of agreement between the researcher and the peer reviewer in application of codes. ATLAS.ti version 6 software (Muhr, 2004) was used to facilitate data analysis.

### *Limitations*

This study involved qualitative data collected from one field site and a small sample of respondents. Therefore the findings presented here reflect the views and observations of these participants filtered through the researcher's subjective lens. To counter this limitation and bolster the applicability of findings, the following attempts were made to triangulate the data: using multiple data collection procedures, recruiting key informants with and without disabilities who represented a variety of displacement settings, and cross-checking emerging thematic insights with disability activists and experts and academic colleagues external to the research.

There were striking similarities between information shared by respondents representing different displacement settings and between information shared by respondents with and without disabilities. There was also considerable consistency between interview data and information gleaned from informal conversations and observations with people with disabilities at the field site.

Another limitation of the study stems from its focus on displacement camps. Therefore findings might not be applicable to displaced populations that might be self-settled or urban-settled, the numbers of which are believed to be rising (UNHCR, 1994-2007). Additional research with these populations is warranted to verify the applicability of these findings. Finally, the study sample included only English-speaking service providers with only two participants having personal experience of disability and displacement. Future research must therefore strive to include more representation from grassroots persons with disabilities.



## *Findings*

Several important insights emerged from the research, ranging from misperceptions about the health-related needs of persons with disabilities to questions of distributional ethics associated with expanding existing healthcare services in displacement camps. Respondents also identified challenges to addressing some disability-specific health needs given significant constraints on existing resources. The research also revealed strategies for making disability-specific health services available in camp settings, including emerging models of community-based rehabilitation and stronger advocacy around disability issues within the humanitarian field. Each of these thematic areas is discussed in detail below.

### **Healthcare needs of displaced persons with disabilities**

Respondents with and without disabilities noted a general lack of awareness among humanitarian practitioners about the health-related needs of persons with disabilities. Respondents emphasized that people with disabilities might have some healthcare needs akin to their counterparts without disabilities as well as some disability-specific needs. This dual nature of needs was believed to be frequently misunderstood by humanitarian health actors who tend to view disabled people's needs as falling squarely outside the realm of mainstream health services.

With mainstream health actors and all actors...feeling that disability is kind of a specialized issue so they don't know to respond, they don't know what to do ... I think one barrier would certainly be the existing mandate and mode of functioning of different health organizations where for them disability services are not necessarily part of health services...[there is need for] more awareness that persons with disabilities do have health needs, some of which are the same as everybody else and some of which are more specialized.

This respondent's observation was corroborated by the many persons with disabilities the researcher interacted with during fieldwork. These individuals reported that health professionals at the camp clinic tended to assume that disabled people only visited the clinic for services related to their disability. Ironically when these individuals presented at the clinic with disability-specific needs, these needs were also not well understood by health professionals.

Among the disability-specific needs identified by respondents, one of the biggest priorities included access to rehabilitation services to maintain physical functioning and to prevent complications from failure of early detection and treatment, such as pressure sores among people with spinal cord injuries and developmental delays among children.

I would say one of the priority needs is immediate rehabilitation care ... that's essential in order to prevent the onset of disability so to really reach people before they become disabled as far as, as much as you can to work in the injury phase to prevent disability or if it's ... a sudden onset of disability like an amputation or spinal cord injury, to do maximum, immediate rehabilitation care to prevent the complications.

Another frequently identified area of need was access to orthotic and prosthetic equipment and technical aids, in particular mobility aids like wheelchairs.

Dire shortage ... of the...equipment they would normally need ... generally any medical equipment be it a wheelchair, be it crutches, be it any form of prosthesis or support you may need, even glasses at times ... I've seen quite a few people actually... who umm would be walking on the floor on their knees and they would have something to cover their ...they don't have a wheelchair so they're walking like that ... there is definitely demand for wheelchairs.

Despite bumpy roads, mobility aids were deemed crucial for accessing key points of service. At one site, there were reports of people with mobility impairments foregoing medication refills due to long distances between their homes and the health clinic. Such examples were brought up by respondents to dispel another commonly-held misperception - that health-related needs are insular and disconnected from other life domains.

For many disabled people, unmet needs, especially for technical aids like wheelchairs, constituted a double setback by hindering their access not only to mainstream health services but also other social services in the camp, thereby negatively affecting both their health and their overall quality of life. "If a person has lost a wheelchair, they're not going to be able to access the world food distribution. So if we can replace their wheelchair, we can give them the independence that they need in order to be able to access other health, camp services."

Respondents also identified the need for mental health services for displaced persons with disabilities. Some respondents noted that while mental health services were being increasingly made available in displacement camps, the access needs of persons with disabilities were seldom taken into consideration when planning and implementing such services.

And the other major need I would say ... is umm psychosocial and mental health services ... which is essential for persons with existing disabilities, persons with new disabilities, to adjust to the emergency, to adjust to the new disability, umm in terms of the caregivers as well to be able to adjust to somebody in the family with a new disability...The problem is often the exclusion of persons with disabilities because of communication barriers [especially for deaf and hard of hearing individuals], not being able to participate ... in the psychosocial services that are set up or accessibility barriers or awareness of the sessions that have been set up.

A final area of need identified by respondents included specialized medical attention in the form of orthopedic or neurological surgeries and pharmacological treatment for chronic physical and mental health conditions such as epilepsy and schizophrenia. Parents of disabled children that the researcher interacted with had made formal requests for advanced medical treatment and/or surgical care for their wards, to no avail. Key informants agreed that this area of need was complex and most difficult to address in the displacement context.

Sometimes for sure medical treatment ... for example in cases of people who have psychiatric conditions or people who have some sort of mental illness and would require umm follow up with that and would require a particular medicine for that ... simply there is shortage of those particular medicines or it's situations which are too complex, are long-term...it's just difficult to put someone on treatment and guarantee the treatment will be available a long time. At times people require surgery for a particular condition or as a follow-up to something that has already been done back home and so on. And when it comes to non-emergency primary healthcare you have to be very lucky if you don't have the means, it's very difficult.

Access to these types of services, in particular rehabilitative services and adaptive equipment, has long been recognized by the United Nations as an important right for persons with disabilities and as inextricably linked to their societal integration and community participation (Chermak, 1990). Additionally, the watershed Alma Ata International Conference on Primary Health Care, jointly organized by WHO and UNICEF, pronounced these services as integral components of primary healthcare for persons with disabilities and essential for realizing the Health for All global strategy (WHO, 1978; WHO, 1981a; WHO, 1981b).

Thus, fundamental to an investigation of healthcare access for displaced persons with disabilities is a consideration of how their health-related needs are addressed within existing systems of primary healthcare established in displacement camps.

### **Healthcare for displaced persons with disabilities: within or beyond the social minimum**

In the theoretical literature driving decisions related to allocation of resources for relief and welfare, the language of 'social minimum' is used to describe the basic bundle of resources needed for a person to live a decent life (White, 2008; Leaning, Spiegel & Crisp, 2010). Combined data from field and desk research revealed that the 'basic bundle' of primary health services available in displacement camps, the social minimum so to speak, comprised such services as first aid, outpatient medical consultation, maternal and child health services, and services related to HIV/AIDS and other sexually transmitted diseases.

The exact configuration of services varied from context to context, with some camp clinics offering limited in-patient care, some offering clinics targeted as specific diseases like tuberculosis or malaria, and others offering psychiatric consultations. However, a consistent trend across contexts was that rehabilitation services were not subsumed under the basic package of health services available. The only exceptions to this trend were Kakuma refugee camp in Kenya and refugee camps in the Palestinian Occupied Territories.

In the case of the former, the International Rescue Committee, which provides essential healthcare in Kakuma, also operates a center for basic rehabilitation services within the camp (Karanja, 2009). In case of the latter, the United Nations Relief and Works Agency for Palestine Refugees (UNRWA) includes physical rehabilitation among the main elements of its primary health provision within refugee camps (UNRWA, 2010).

Across most of the other displacement contexts represented by the study respondents, rehabilitation services were not included with other health-related services within the camp. “There is a clinic for everybody which treats malaria, diarrhea and like that. But a clinic which concerns things like some kind of disability, we don’t have ... and when we go there, they say that, they used to say that ‘Ah we don’t have this service for disabled so you can remain at home because we cannot assist you, we are not able to assist you. We don’t have enough materials to assist disabled’.”

The situation was reported to be even direr among camps hosting internally displaced persons since these camps were typically lacking in resources brought in by UN agencies and international NGOs. “People in IDP camps...are much more isolated and they aren’t official refugees so they aren’t able to get much support from NGOs...overall there are more options available to the refugee camps as there are to the IDP camps whether it is for health, whether it is for education, income-generating opportunities, all of those things.”

Moreover, in IDP camps, where health services were dependent on referral hospitals run by the local Ministry of Health, the focus tended to be on life threatening conditions over chronic and long-term conditions related to disability.

Most refugee camps ... do not have set up of health services and are mostly benefiting from outreach services of surrounding hospitals. The interventions of most of the referral hospitals through outreach is normally to respond to emergency situations...In cases where there is influx of refugees, government priority is to save people from life threatening conditions. Normally government says that disability is not life threatening, so focus is on treating malaria and contagious diseases which can turn into epidemics.

Some respondents suggested the integration of rehabilitation services within mainstream healthcare as an important priority in the health arena, especially in situations with large numbers of persons with disabling injuries.

In most of the contexts that I have worked in, we have noticed that there are not specialized services for disability... I would say whenever there is an emergency with lots of injuries the priorities should be ensuring that rehabilitation services are integrated into health services ... I think that’s across the board but in terms of priority, it’s a priority when there’s injury.

Exclusion of disability-specific services from the ‘basic bundle’ of health services available in camps did not, however, mean that these services were entirely unavailable. In some situations, elaborate mechanisms had been developed for referral of persons in need of services to external facilities.

Here in the clinic we don’t really have any services for refugees which are specialized or anything like that. It’s quite basic. But we have an excellent system for transferring cases. So for example if they cannot be treated in the clinic in the camp, we can transfer to the district

hospital and if not we can transfer to the main hospital in [capital city]. And then again if they still cannot be treated we refer them to private hospitals within [country] and UNHCR pays for 100% of all that including food and transport and all necessary treatments.

While referral mechanisms, such as the one alluded to above, had been put in place to facilitate access to services, they also presented their own set of barriers. By virtue of falling outside the 'basic bundle' of care, access to rehabilitative services had to be negotiated by navigating through layers of bureaucratic complexity. In one camp, this navigation involved multiple steps: getting a referral from the camp clinic to visit a specialist at the nearest district hospital, lobbying with UNHCR to get permission for the same, applying for transportation and financial assistance from the designated social service agency, and finally securing permission from the camp administrator to leave the camp premises.

You'll have to go and see a specialist in [capital city] and that in turn is very difficult to do... it's a lot of hassle...to set up...if the clinic did not refer you to that specialist unit...I think you would have to go and see the UNHCR, you would try and lobby for you to try and get into that clinic. It's a very, very kind of, stuck in the mud kind of, it's, nothing flows very much with healthcare...you have to get permission from the camp administrator...and...it's a 30 or 40 minute drive on...bumpy roads ... it's a long way for someone here and the political situation kind of doesn't help either.

Navigating the multiple steps involved in getting access to rehabilitation care outside the camp was also heavily dependent on inter-agency co-ordination. This meant there was a high likelihood of referred cases, and with them disabled persons' needs, being met after long delays at best and falling through cracks in interagency co-ordination at worst.

Even to get a pair of crutches. I mean take Peter's case, for months and months he was asking for umm crutches, he was going around with two sticks with the thing at the bottom of it. I think he only got them about...a month and a half ago ... cases can fall through the cracks ... between inter-agency referral systems ... when it comes to access...to the relevant medical equipment that's a generalized problem. I mean even if you have an NGO which is tasked ... with distributing that sort of thing, procuring that sort of equipment, either the demand is too vast or they don't have the resources ... But somehow it does fall through the cracks very often.

Peter (name changed) referred to in the above quote was finally able to procure the crutches he needed through a humanitarian staff member's personal donation. During fieldwork, this researcher came across others like him who had either waited for long periods or were still waiting to get mobility aids such as wheelchairs and orthopedic shoes. Even in situations where individuals were successful in navigating the steps involved in getting the referrals they needed, follow-up services to monitor their progress were found to be lacking.

If we can have one specialist here at the clinic ... who is specially looking into the health needs of the physically challenged. Because the current system does not allow that most of the times ... we found sometimes there are not proper follow-ups when you refer a patient

For some disabled people, the complicated process of inter-agency referrals and permissions frequently came to naught. These were mostly individuals with advanced medical and surgical treatment needs, which could not be met through existing healthcare systems in the host country.

Normally disabled [person]...tries to seek and get a treatment but it's not easy because UNHCR sometimes they send out to hospital ... But if this hospital, if it fails to treat the disabled ... you are transferred to [district hospital], sometimes the doctors say no according to the kind of disability you have, they may transfer to [other cities] so after that the doctors sometimes they transfer out of [country] to be operated or to get the treatment out of [country]. But when they presented the papers, the documents to UNHCR, they have never responded [to] that ... So that's a big, very big problem we have.

This respondent was referring to requests for advanced medical and surgical treatments, which could not be met because of limited local availability of specialized treatments and funding shortages. Concerns about the latter appeared to have triggered distributional dilemmas between providing specialized surgeries/treatments requested by camp residents with disabilities versus covering generic health needs of the overall camp population.

### **Healthcare for displaced persons with disabilities: distributional dilemmas**

Information gleaned across respondents indicated that advanced medical and surgical treatments represented needs that were so far outside the 'basic bundle' of care that they called into play difficult and uncomfortable decisions about competing needs and distributional trade-offs.

When it comes to health services ... they have list of people who need operations for example, medical intervention. That list is for priority you know if somebody who has something with walking or needs an operation to modify their feet or something like this, they will not consider it a priority than somebody who has ... cancer or something, you know emergency, she will die or heart problem, she will, she will die if she will not get it or kidney problem ... there is a prioritization for health problems, then they take those people. And these people, they have to wait. Because ... they will not die if they will not do those operations ... It's financial problem.

As a counterpoint to this comment, other respondents reported situations where persons with severe disabilities had died from unmet medical and surgical needs, their needs having been sidelined as "non-emergency" issues. This was also the unfortunate outcome in a few cases

where needs were more basic such as special food rations for disabled persons with swallowing difficulties.

Thus, even in the absence of competing demands for life-saving treatments, any request for specialized services had to be weighed against the overall needs of the camp population. For instance, at the field research site, the entire camp population was dealing with shortage of essential supplies such as soap and cooking fuel. This situation was not unique to this site and was reported to be prevalent in other displacement camps as well.

I have a budget ... allotted to the camp. How much can come out of it, how many cases can I cover in this camp...which have more than 30,000 person ...[including] many persons with disabilities ...? Perhaps ... we can cover two to four of the medications in a year and umm perhaps I can provide three or four wheelchairs ... that's all ... Because we have priorities...[whether] we find ... professional services for people with disabilities or you want to, to cover the basic issues for all, all of the general people.

These comments and examples highlight an important point - within the context of displacement camps, often characterized by limited resources and vast needs, any service request that pushes the boundaries of the 'basic bundle' of care beckons deliberations over distributional ethics. For persons with disabilities, this portends a perpetual 'us versus them' situation, with many of their health-related needs configured outside the 'basic bundle' of healthcare and therefore constantly measured and pitted against needs of other camp inhabitants.

Recent literature in the humanitarian field, in particular the work of Leaning, Spiegel and Crisp (2010) has tackled the issue of 'exceptional' healthcare needs of displaced populations within the framework of public health equity. The authors observe that the aging of refugee populations the world over might well create a situation where more and more people request 'exceptional' healthcare thereby warranting a strategic shift from making exceptions on a case-by-case basis to raising the 'social minimum' of care for all persons.

This possibility was discussed with respondents, many of who found it infeasible in the face of funding exigencies and service pressures. Respondents expressed concerns about parity of services between refugees and host communities with the latter being described as equally, if not more resource-constrained than the former. Consequently, agencies operating in refugee camps were described as being obligated to open up health services to host communities. In some situations, this had resulted in enormous demand for services and even driven down service standards.

In the displacement camp where fieldwork was conducted, common healthcare-related grievances included dire shortage of basic drugs and lengthy wait times at the camp clinic, which was equipped to serve 10,000 people but was instead serving 40,000 locals from the surrounding villages in addition to the refugee residents of the camp. In another camp, 60% of the clinic's clientele were reported to be members of the host population. Given these realities, expanding the 'social minimum' of healthcare was thought to be highly unlikely short of a funding windfall or a steady stream of consistent funding.

In order to promote good community relationships with the refugees and people surrounding the camp, they also have access to the [camp] clinic. So we have very much overcrowding problem now ... it affects the quality and quantity of services, which you can get here...If we could reduce the number of [locals] who attend there if there was one that was closer to the village or of equal standards then the services provided here would be fully for the refugees which would be ... much better. Not to discriminate against the [locals] but we just can't cope with the number of people and at the same time we don't have money to build clinics for the whole country right?

Sustainability was another concern related to expanding the 'social minimum'. Some respondents were apprehensive about host governments' ability to sustain specialized and high quality services set up by international NGOs.

I think it's quite clear that each country has its own capacity to deliver to a certain level. So when you look at sustainability and you are there as an NGO and you can provide services and try to provide better but the hope is always that at some point that will have to be handed over ... to the local system, to the local government and local health ministry and so on. So you find that at times the standards of services delivered by NGOs is also higher than what is being actually given to the local people ... you're operating with system of a country which has its own policy so one needs to also ... take those into consideration whenever you're developing something new.

The discussion thus far indicates that disabled people living in displacement camps encounter barriers to accessing mainstream and disability-specific health services. Health needs in both categories are intertwined. Unmet needs in the latter category, in particular access to health-related rehabilitation services and adaptive aids, can lead to long-term complications and further hinder access to mainstream health and social services available in camps.

Furthermore, these services are not included in the basic healthcare bundle available in camps and are therefore not only harder to access from a user perspective but also harder to set up from a provider perspective. Lack of health-related rehabilitation care was brought up repeatedly by disabled people and parents of disabled children this researcher interacted with during fieldwork. This topic was examined more closely with key informants who discussed the various challenges and opportunities related to these health needs.

### **Addressing health-related rehabilitation needs in displacement camps**

Making health-related rehabilitation care available to people with disabilities living in displacement camps was reported to be heavily dependent on the existing infrastructure in countries of first asylum.

It depends a lot on what the host country is willing to provide umm in terms of services for the refugees. And otherwise, it's a very umm



NGO umm centered service because you're working...in a host country ... it varies very much from context to context. It's dependent a lot on ... what was existing before, the nature and the volume of the crisis as well.

Most respondents suggested that provision of adaptive aids and basic orthotic and prosthetic equipment was easier to put in place as it required fewer material resources and less specialized human skills.

Technical aids, that could be something that's met a little bit quicker ... It's a little simpler to put in place ... Say in terms of rehabilitation and in terms of human and material resources, it's a little bit easier to put in place.

Indeed, programs have been developed in and around displacement camps in Dadaab, Kenya and along the Thai-Burma border where international NGOs have made financial and logistical investments in building local capacity to manufacture artificial limbs and basic mobility and self-care aids (Women's Refugee Commission, 2008; Handicap International, 2009). Conversely, in IDP camps in Uganda, material for manufacturing wheelchairs and artificial limbs was reported to be cost-prohibitive. Consequently, only a handful of requests for such equipment were reportedly honored through UNHCR/NGO programs for "extremely vulnerable individuals".

In other camps in Malawi and Yemen, UNHCR and its operating partners had forged agreements with local Disabled Persons' Organizations (DPOs) for manufacture and dissemination of technical aids. Partnering with local DPO's was deemed more cost-effective and therefore more feasible and sustainable than bringing in expatriate technical expertise. Such partnerships had also created opportunities for goodwill and cross-exchange of disability rights information between host DPOs and disabled refugees.

All assistive devices [refugees] can get because there is a big workshop at the centre ... we have annual agreement with them and we provide them with financial, an amount but it's not expensive. They, they sell it to us like for [locals] and umm because it is a local NGO, it's not expensive. Usually international NGOs are very expensive.

Thus, mechanisms to provide technical aids for displaced persons with disabilities had been more or less feasible despite limited funds. In contrast, organizing health-related rehabilitation services such as physical, occupational and speech therapy had been more difficult. Providing these services was seen to be contingent on availability of trained professionals, which according to one respondent, varied widely from context to context.

If I think of the camp in Gaza ... We had a huge team of local Palestinian physiotherapists on the ground during the incursion of 2009. We had all the services that we needed after the emergency. But if a country where that level of health professionals actually didn't penetrate, if you take the complete polar opposite which is Haiti there was no rehabilitation training before the earthquake.

The greater availability of specialists in Gaza and the West Bank may reflect investments by UNRWA and foreign donors in training Palestinians in allied health professions after the the first Intifada (UNRWA/UNESCO, 2004-2005). In comparison, the dearth of locally trained professionals, while certainly extreme in case of Haiti, also appeared to be true of other displacement contexts represented in this study, such as Malawi, Uganda, Yemen, and the Thai-Burma border.

In Malawi, for example, there were only twelve physical therapists by the year 2000, one aspect of the overall dearth of qualified health professionals in the country (Lavy et al., 2007). This situation also mirrors the global picture of rehabilitation services with trained rehabilitation professionals reported to be accessible only in one third of low-income countries at the local level (WHO, 2001).

Lack of locally trained professionals was identified by respondents as a major hindrance in making health-related rehabilitation services available to displaced persons with disabilities.

Unfortunately ... [we're] not really developed in this field...we have two centers and these are the most developed centers...But when I go there and I talk to them ... I look at the level of the people who work in the intervention programs, early intervention and the other sections ... They will need a lot of training and some space to develop their skills.

Issues in the camp pretty much reflect the general picture of the health situation [in this country]...It is a field which has a dire shortage of human resources. I don't know if there are any public universities with faculty of medicine ... As far as I know there is one private university that has faculty of medicine. A lot of the people who go through nursing train in the UK and never come back. So it's just a huge brain drain when it comes to health.

I get very frustrated. I don't get frustrated with refugees, I get frustrated that we can't do anything for them because of this ... I meet with the parents [of disabled children] on a regular basis ... to find out what's going on. And every time, every time, despite how many times I tell them ... I'm not a doctor, I can't do anything for them medically, they're like 'I need medical help, can you do this, can you do that for us' ... And I'm like 'Well what do you want me to do...there is nothing ... [this] is not, it's not the UK, it's not the United States, it's not Europe. There are no kind of rehab[ilitation]...So it's very frustrating.

In one setting, respondents reported the existence of only one center (established and supported by a western-based charity) in the entire country that had the capacity to provide health-related rehabilitation services. The center was reportedly overwhelmed with the needs of the host population thereby diminishing any possibility of tapping into its expertise to meet the needs of disabled persons living in the refugee camp.

There is one organization in [capital] ... And I think they have one speech therapist, one physiotherapist, and two or three other qualified

specialists. We're talking about less than five catering to ... quite a large population and this is by far the most specialized service in the country. So the need is great and there is just no one really, people to provide the services ... so it's very difficult to book an appointment with them for therapy regularly for example, trying to reach them, it's not sustainable ... we can't really assist them [refugees] much with that.

In the above setting, one humanitarian worker had tried to arrange for specialists from the rehabilitation center in the capital city to visit the displacement camp. After sustained effort, physical, speech and occupational therapists from the center visited the camp to assess all children with disabilities. Many of these children were referred for ongoing and regular therapies at the center but were unable to avail of these referrals owing to transportation barriers. The camp clinic had only one ambulance on standby, which could not be dispensed to transport individual families to the rehabilitation center several times a week. Frequent fuel shortages in the country also meant that the ambulance needed to be used judiciously. Transportation, when available, was only one-way to the clinic and there were reports of families selling food rations for the return fare.

The thing is that they cannot get transport every single day and...they don't have the right to live outside the refugee camp. It's a government policy ... So for people who need physiotherapy everyday or for kids who need daily assistance from [rehabilitation clinic in the city] or attend services there, the parents are not able to live outside the camp and they're not allowed to afford transport we can provide the transport only once per week or twice per week for the families. So it's a great challenge for them to access regularly.

There is an ambulance for, it is free for everybody. But the problem is this, if the ambulance takes you in the morning, you are on yourself to take you back from there. You have ... to pay your money for ticket. Well we don't have ticket ... Or we have to sell some quantity of food in order to get some transport from [town] to [camp].

Some families had made formal applications for procuring bus fare from the NGO in charge of social services. By the time their applications were approved, they had missed their appointments. Another barrier stemmed from the host country's forced encampment policy which meant that camp residents needed to secure special permission to leave the camp or risk being returned from security check points installed to regulate access to and from the camp. Living closer to the rehabilitation clinic was also not an option for many families owing to limited funds (they would have to support themselves when living outside the camp) and the risk of being detained by immigration authorities.

One child in particular ... all the family actually lived in [capital city] and were attending the clinic on a regular basis ... They were being sponsored by someone ... but the sponsorship dried up and in the end they had to ... leave it because they couldn't...afford to go and also without sponsorship ... they lived a fine line with the authorities.

Since the ability to travel and live outside camps is restricted in many host countries, another strategy that had been tried in some settings was to bring expatriate professionals into camps for brief periods of time in conjunction with using low cost mechanisms to sustain the benefits of their expertise after their departure.

We had a [Dutch] volunteer ... a prosthetic tech[nician] that can do umm physical therapy. She did a chart that shows exercises...to strengthen the limb that had the prosthetic ... with pictures just a few words, something that can be put up on the wall and that was a big boost coz then that can be put in workshops and they were distributed inside other places around ... the camps.

While bringing in expatriate professionals had worked in some instances, in others the challenge had been to find adequate housing and other facilities close enough to the displacement camp to host these individuals. Another reported challenge of bringing in western-trained professionals was finding people with enough developing-country experience for their services to be meaningful in the local context.

It is hard to attract medical personnel to stay close to a refugee camp so as to provide health services on a constant basis as there is normally lack of facilities like housing among others.

Finding people in itself has not been challenging at least not for us ... We tend to not bring in volunteers however though. We bring in people that stay for, umm you know longer periods of time for some capacity building. We haven't had a huge difficulty finding people. We've had more difficulty finding people that have had a...developing country experience before that.

Despite difficulties with bringing expatriate professionals to serve in camps on a long-term basis, respondents were firm against using volunteer professionals as a stop-gap measure. Volunteer-provided services were described as being ad hoc, less reliable, unsustainable, and generally difficult to support given volunteers' inexperience in local context and culture.

Sometimes volunteers are more work than they are help...it takes a while for the volunteers to get going and to start building a relationship ... And then just getting logistically oriented to wherever they are they also need someone to mentor them or check in whatever so if it's just somebody that's just looking for a holiday adventure and to be able to say they did something, to me that isn't worth our time or our partners' time. The other thing is a lot of times I have worked to set up a situation and then at the last minute, for good reasons, the individuals have [said]'Oh I can't make it after all'. So then you have all the expectations and then it falls through. So that's happened more times than the other way around.

Taken together, the concerns and challenges identified by the respondents signified the need for a long-term and locally-sustainable model for providing rehabilitation care in camps.

## Community-based rehabilitation and task shifting

The Community-based rehabilitation (CBR) model first emerged in the mid-1970s in response to staggering disparities in access to rehabilitation services in developing countries (Charmak, 1990). Drawing upon the principles of primary healthcare, the model emphasized local capacity-building to counter shortage of trained rehabilitation professionals in resource-constrained settings (Hartley, Finkenflugel, Kuipers & Thomas, 2009). CBR has been long promoted as a model for assisting displaced persons with disabilities (UNHCR, 1996). The early CBR model, as well as UNHCR's initial endorsement of the model for use with displaced populations, had an exclusive medical rehabilitative focus. However, over the years, the CBR model has expanded in scope to encompass community-wide efforts toward disability inclusion across the domains of health, education, livelihood, social life and empowerment (WHO, 2010).

This study identified ongoing CBR programs in many displacement camps. Some of these programs were well-established while others were in nascent stages. Established programs included programs in Kakuma and Dadaab refugee camps in Kenya, Bhutanese refugee camps in Nepal and Kharaz camp in Yemen.

With regard to health-related rehabilitation care, a common feature of all these programs was the training of 'disability community workers' to carry out home visits for counseling and basic physical and occupational therapy (Women's Refugee Commission, 2008; Karanja, 2009). This model was seen as relevant for setting up emergency as well as long-term rehabilitation services in displacement camps.

When there is a pre-existing CBR model what's interesting is having penetration very quickly by the networks that are already existing in countries ... Where it's not existing sometimes [programs] you set up in an emergency...have actually morphed into CBR programs afterwards ... There's lots of aspects of CBR that can be used in emergency for example the whole concept of having a holistic approach towards the beneficiary, to meet all of their needs and trying to have a local network umm local capacity-building to be able to respond to multiple needs of persons with disabilities.

In some displacement settings, CBR programs had developed spontaneously while in others, they were the result of deliberate policy decisions at the organizational level. An example of the latter is UNRWA's policy decision to move away from providing direct services and toward supporting the development of CBR centers as a way of strengthening beneficiaries' "capacity to formulate and implement sustainable social services in their communities...[and] to promote self-reliance through participation and empowerment" (UNRWA, 2010). Conversely, in other settings like Malawi, for example, a rudimentary CBR program had emerged to fill in the need for rehabilitative services for children with disabilities in the absence of qualified specialists.

So knowing that there is very much a shortage of experts ... we said ok if we cannot help the children, what at least can we do for the parents? So we set up a, a kind of a respite care program where basically the parents of these 20 children can leave their children for a few half days

per week ... they can go and attend their other activities. And we trained 20 volunteers umm over a three-month period on how to care for these children ... basic physiotherapy, nutrition and diets and also writing and painting and teaching them to eat on their own and such things.

This program is especially notable because it was developed collaboratively between UNHCR, an international NGO, and the camp's Disabled Person's Committee, an enterprise led and initiated entirely by refugee residents of the camp. Parents utilizing the program frequently extolled its virtues during interactions with the researcher. An observed outcome of the program was greater community awareness about disability issues. The disabled leaders of the program, the non-disabled volunteers, and parents of children with disabilities had forged strong bonds and had jointly organized a solidarity march on International Day of Persons with Disabilities.

Disability group is acquiring visibility in [camp] due to the respite care program, due to, now the process of, the practice of celebrating international disability day, somehow the issue is coming out.

This example illustrates how CBR programs developed with grassroots collaboration can serve as nuclei for generating disability awareness within displacement camps. Though this program was successful in its own right, it was developed to meet gaps in access to rehabilitation care, which continued to be a problem in the camp. Evaluations of CBR programs in other displacement settings have also identified unmet health-related rehabilitation needs mostly due to lack of requisite training among community disability workers (Center for Persons with Special Needs, 2007; Siyat 2010).

A notable exception in this regard is the CBR program in Kakuma, Kenya which includes an on-site physical therapist and a visiting occupational therapist to train community workers (Karanja, 2009). In other displacement settings and across CBR programs in general, lack of health-related training and capacity continues to be a limitation (Evans, Zinkin, Harpham & Chaudury, 2001; Deepak, Kumar, Ortali & Pupulin, 2011).

To combat this limitation, respondents proposed a "train the trainer" approach, where arrangements could be made to have trained professionals visit camps intermittently to train and supervise community workers as well as to help strategize emerging needs.

I'm a big advocate of 'Train the Trainer'. So if you had somebody who could come in umm or a whole team go into camps. And I also like the idea when you replicate things so let's say you had a team that could go from camp to camp and train the people in the camp, that would be wonderful.

The "train the trainer" approach, or the idea of training mid-level or less specialized health workers to fill gaps in health provision, is being deliberated at the policy level by influential actors in the humanitarian health community. The WHO as well as a growing consortium of humanitarian health providers endorses the policy of 'task shifting' or training mid-level health providers as a potentially useful strategy to counter pervasive human resource shortages in humanitarian healthcare (WHO, 2007; VanRooyen & Burkle Jr., 2009).

With regard to health-related rehabilitation care in displacement camps, precedent for task shifting dates back to Thai-Cambodian refugee camps of the 1980s (Dunleavy, 2009). Lessons learnt from this endeavor could be usefully revived to guide future 'task shifting' efforts.

While respondents agreed that strategies such as CBR and task shifting might offer a good starting point for filling some healthcare gaps for displaced persons with disabilities, they also stressed the need for greater advocacy around disability issues as crucial for the development of more inclusive and responsive humanitarian health programs in the future.

### **Developing inclusive and responsive humanitarian health programs**

Several respondents suggested that developing humanitarian health programs to be more inclusive of and responsive to the needs of persons with disabilities would be difficult without significant financial support from donors, which, in turn, was seen to be dependent on political will to rally around disability issues and sensitize donors about the same.

Funding for sure, sensitizing donors as to the need...that's definitely a challenge ... UNHCR acknowledge they're not doing enough. But obviously their funding is not self-fund-raised, it comes from donors, so finding donors who are willing to worry about it [disability] ... as well as reviewing current service-provision and making sure that it is inclusive. That needs planning, it takes restructuring. So there needs to be will and there needs to be means to do that as well.

Respondents differed in what they viewed as effective strategies to generate greater disability awareness among humanitarian actors and donors. Some believed that stronger disability consciousness was needed at the highest levels of the humanitarian chain and that a dedicated disability agency at the level of the United Nations was necessary to drive this agenda. Others advocated for diffusion of disability awareness, suggesting that disability was too much of a cross-cutting issue to be under the mandate of a specialized agency.

Something like that needs some kind of seismic change...If you're gonna really...deal with an issue, then you really got to deal with it, you can't keep it on the fringes...you can't marginalize the issue ... and it needs to come from high up ... everything in, in the humanitarian sector really is coordinated by the UN so you can't do anything without the UN giving the say-so, really ... So I would say it really needs to come from the United Nations ... I'm sure they're not going to make up a UN agency for disabilities but, but that's what it needs probably. Because then UNHCR will take it seriously because they're being pressured ... other UN agencies to do something about that particular issue.

Disability is a bit of a challenging domain in the sense that it's not a domain that stands on its own. A lot of organizations when you look at them and at the way that they function...for example Oxfam that has a very large focus on water and sanitation umm MSF, Doctors without

Borders that has a focus on medical care and so on. A lot of actors focus on specific sectors. Disability is challenging because it's not one sector...disability cuts through all sectors so it does make it a little bit more challenging umm to sort of look at it from a mandate from an organization perspective.

Recently, there has been political traction around disability issues at the higher levels of the humanitarian field. Examples include: adoption of the UN Convention on the Rights of Persons with Disabilities, statements from the UN High Commissioner on Human Rights expressing concerns about the plight of displaced persons with disabilities, release of Executive Committee conclusions on people with disabilities assisted by UNHCR, and greater involvement of disability-specific actors such as Handicap International and the International Disability and Development Consortium in the humanitarian field (Executive Committee, 2010; United Nations Commission on Human Rights 2010).

Respondents acknowledged that these developments augured well, but they also expressed reservations. There were concerns that while other humanitarian sectors were becoming more astute to disability issues, the health sector was still lagging. Additionally, disability-friendly rhetoric was deemed too slow in trickling down to change ground-level realities.

I must say that I'm seeing a change in other domains outside of the health sector ... where slowly, slowly you do see large humanitarian actors that are present in a lot of the emergencies umm where through sensitization by different disability specialized organizations they tend to take into account accessibility features a little bit more and more.

Internationally there is growing understanding and awareness about disabilities and about what it takes in an emergency context to make sure that services are you know accessible. But by the time the discourse filters down to the ground level, to the camp, it takes a very long time. So you can have an international policy and a wonderful convention and policy papers and protocols and all that but then ultimately it's the behavior on the ground and the people who are living in the sites which makes the difference...whether you're able to access a service or not.

The scepticism about translation of discourse to action is important, and especially salient in comparison with other prominent issues on the humanitarian radar, which have better survived the pathway from institutional rhetoric to tangible changes. For example, issues such as sexual and gender-based violence (SGBV) and HIV/AIDS have, in recent times, garnered significant attention not only at the level of humanitarian policy-making but also within field operations and activities (UNHCR, 2005; Rothkegel et al., 2008).

Fieldwork conducted during this research indicated that SGBV and HIV/AIDS were prominent areas of concern drawing considerable energies and resources in the field site. Murals and slogans addressing SGBV and HIV/AIDS awareness had been painted on walls in high-traffic areas and committees had been created for community education on these topics. In comparison, the disability committee in the camp had been initiated and organized by the disabled residents



themselves who, disillusioned with the lack of services for disabled people and “after seeing how people living with disabilities are discriminated”, decided to organize a collective by reaching out to other disabled people through faith-based centers and radio announcements. The purpose of this collective was primarily to make people with disabilities and their needs more visible in the camp.

[our] purpose was just to tell people living with a disability how can, we can fight for our rights ... since that was, it was not respected by the community. And the second thing...if we can show the government ... UNHCR and other organizations dealing with refugees our existence in [camp] because normally, other people didn't know if we are existing in [camp].

In their efforts to make disability issues more prominent in the camp, members of the disability committee found themselves both aspiring toward and simultaneously competing with more prominent issues like SGBV and HIV/AIDS. One area of contention was that unlike other ‘special’ groups such as women victims of violence and people with HIV/AIDS, people with disabilities did not enjoy group-based access to special programs in health-related areas such as rehabilitation therapies and supplemental feeding programs as well as in non-health areas such as vocational training and resettlement opportunities.

Members of the disability committee had also clashed with institutional actors over merging the camp's disability day celebration with commemoration of HIV/AIDS and SGBV campaigns in the camp. What was seen by institutional actors as an opportunity to ‘mainstream’ disability awareness was ostensibly seen by the disabled people's collective as co-option and obscuring of their efforts for greater visibility by other more visible issues in the camp. The permeation of SGBV and HIV/AIDS programs across humanitarian field operations was seen to be the result of aggressive and sustained advocacy, the likes of which would need to be replicated in order to encourage similar uptake of disability-related issues.

These [SGBV and HIV/AIDS] are very sexy kind of issues within humanitarian kind of worlds. Disability I don't feel is a sexy kind of like an issue ... if you say ‘hey now’, there's a huge global day of HIV/AIDS and everyone knows about it...in theory, 10% of the people in the world aren't afflicted by HIV/AIDS and 10% of the world .... haven't been raped ... 10% of the people in this world **are** affected by disabilities ... HIV/AIDS is a hot topic here because people are there pushing ... there are meetings with you know in the government that say HIV/AIDS, HIV/AIDS, HIV/AIDS. Why is there not somebody in a meeting saying disabilities, disabilities, disabilities?

Specifically, in the humanitarian health arena, the disparate attention to disability versus other areas could also be interpreted as reflective of the global armamentarium driving the mobilization and allocation of resources and the prioritization of social and health issues in the developing world. Both HIV/AIDS and gender-based issues are included among the United Nation's Millennium Development Goals while disability is not (United Nations, 2005; Groce & Trani, 2009).

Accordingly, foundations awarding grants for improving healthcare in developing countries have focused heavily on HIV/AIDS and reproductive and sexual health (Behrman, Behrman & Perez, 2009). Heavy emphasis on these issues has deflected attention from other areas, possibly resulting in other significant health conditions, including disability-related conditions, being neglected within the global health and humanitarian agenda (Olusanya, 2007; Behrman et al., 2009).

## **Conclusions and future directions**

Much academic and advocacy work on disability issues tends to be dominated by norms that have emerged from the Global North and is being increasingly called out for ignoring important issues affecting the majority world. One of these important yet ignored issues includes access to appropriate health care, which is taken for granted in affluent societies but threatens the basic survival of people with disabilities in resource-constrained settings (Meekosha, 2008; Miles, 2011).

The present research showed that this is an important area of concern within the context of displacement camps. Many of the study findings are corroborated by a recent WHO report related to unmet health-related needs and healthcare access barriers faced by people with disabilities living in resource-constrained settings (WHO, 2011).

To summarize the findings of this study, people with disabilities living in displacement camps have health-related needs some of which are generic and overlap with needs of the broader population of displaced persons such as primary healthcare and mental health counseling; other needs are disability-specific such as curative, preventive and maintenance-based rehabilitation services, technical aids and devices, corrective surgeries, and medical treatment for chronic health conditions.

Unmet needs in one area reinforce needs in the other as well as hinder disabled persons' participation in other social programs thereby hindering their overall quality of life. To the extent that adequate primary and mental health services exist in displacement camps, unmet needs mostly stem from physical and communication access barriers. On the other hand, disability-specific needs mostly fall outside the 'basic bundle' of health services generally available in displacement camps. Consequently, efforts to address these needs are hindered by funding shortages and bureaucratic complexities.

Some disability-specific needs such as surgical procedures and long-term medical and pharmacological treatment for chronic health conditions fall far enough outside the 'basic bundle' of care to raise questions about distributional ethics, with concerns that allocating scarce resources to address the specific health needs of a few might jeopardize the health of the overall population. Expanding the 'basic bundle' of health services in displacement camps might be deemed infeasible owing to scarcity of funds, concerns about equity of services between host communities and displaced populations, and skepticism about the local sustainability of new services established by humanitarian actors.

However, as pointed out by Speigel and Crisp (2010), UNHCR's HIV/AIDS programs are a fitting example of why these challenges are not entirely insurmountable. The HIV/AIDS

programs serve as case in point demonstrating that political will and resource commitment can result in innovative strategies to integrate previously ‘exceptional’ conditions into regular healthcare delivery in displacement situations.

Access to appropriate healthcare for persons with disabilities is an area that warrants further attention and action from humanitarian practitioners and policy-makers. To this end, specific practice and research directions are offered below. None of these directions can be undertaken without close partnership and involvement of people with disabilities living in displacement camps.

An important first step, therefore, is to support collectives of people with disabilities where they exist and facilitate the development of collectives where they do not. As evidenced by data from this research, such collectives can be important partners in identifying existing needs and in planning and implementing services to address unmet needs whilst being respectful of disabled people’s rights and preferences.

The CBR model offers a useful operational framework for addressing some of the health-related needs of persons with disabilities in displacement camps. The CBR framework is broad and encompasses domains beyond health and rehabilitation care. Within the health domain, CBR programs can support primary health clinics in displacement camps, identify and monitor rehabilitation needs and where possible, and implement services to address these needs.

This research uncovered multiple examples of CBR programs underway, some better established and more extensive than others. This variability in the nature and quality of services is not surprising given that field operations across displacement settings are dynamic and uneven with a disparate array of UN and non-UN humanitarian agencies providing services across settings (Rey, 1999; Minnear, 2002).

CBR programs in different settings have evolved differently most likely as a result of the disparate philosophies and practices of the different field agencies operating in each setting. The involvement of multiple actors not only creates disparities between settings but also leads to fragmentation of efforts and offsets opportunities to share information. One strategy to redress this situation would be to strengthen coordination of activities and information-sharing among agencies through the establishment of a working group akin to interagency working groups on reproductive health and children’s health in displacement settings (Rowley, Reis & Lawry, 2007; CORE Group, 2008).

Coordination between agencies as also future development of CBR programs can be augmented by additional research, specifically site-specific and comparative case studies to document best practices and outcomes of CBR programs. Systematic comparisons of programs across multiple sites is indispensable for developing the evidence base of humanitarian health practices, the need for which is pressing and the dearth of which continues to plague the field (Banatvala & Zwi, 2000; Mock & Garfield, 2007; Spiegel et al., 2010).

There is also a need for operations research to inform the planning and implementation of CBR programs that are optimally designed according to the contingencies of each displacement setting. As evidenced in this research, displacement contexts vary in ways that might influence

the success and sustainability of CBR programs. Characteristics of the displaced population, the availability of human and material resources, the political climate, and the geographical landscape of the setting are all locally contingent factors that need to be addressed in the development of CBR programs.

Operations research, based on techniques of mathematical modeling and optimization (Beamon & Kotleba, 2007), can be useful in comparing local factors unique to each setting and selecting the best and most cost-effective configuration of resources given available alternatives. Availability of site-specific data at the local level would be key to this research and programmatic agenda. The roll out of UNHCR's 'proGres' registration system (Women's Refugee Commission, 2008) in various displacement camps offers a good source for gathering population level data on numbers of persons with disabilities and their needs.

Data on variables, such as local availability of trained professionals, availability of transportation, distances between camps and nearest rehabilitation clinics, and host government policies vis-à-vis freedom of movement for refugees, can be obtained from field agencies operating in each setting. The establishment of university-humanitarian agency collaboratives (Mock & Garfield, 2007) can help build capacity to collect and analyze data while opening up the possibility of replicating the research process to help design interventions in other health sectors.

While best practice case studies and operations research can help illuminate the amounts and kinds of research needed to adequately meet the health-related needs of displaced persons with disabilities, research in and of itself is not enough to resolve resource shortages. Based on the findings of this research, human resource shortages are a major factor hindering the provision of adequate healthcare to this population.

While some disability-specific needs such as technical and adaptive aids appear to be easier to address within the context of displacement camps, other needs such as regular access to rehabilitation care are significantly hindered by the dearth of trained professionals. The dearth of rehabilitation professionals mirrors human resource shortages in other areas of healthcare and signals the need for the humanitarian health community to make concerted efforts to redress this situation.

The WHO strategy of 'task shifting' offers a promising direction for such efforts. As the humanitarian health community deliberates the necessary steps in this direction, discussion of health-rehabilitation care should be included. In many displacement settings, there is a dire need for mid-level professionals and community workers to serve existing CBR programs.

Local disabled persons' associations can play an important role in both recruiting and monitoring the training of these new cadres of rehabilitation workers. The proliferation of communication media for organizing humanitarian relief offers additional opportunities to remotely support CBR programs through cell phones and Internet technology and warrants closer attention (Harvard Humanitarian Initiative, 2011; WHO, 2011)..

Another important factor impeding development of services for persons with disabilities is related to funding. There have already been calls for UNHCR to increase its budget allocation for

health services (Leaning, Spiegel & Crisp, 2010). Along with increasing the overall health budget, it is imperative that UNHCR and other humanitarian NGOs secure additional funding if they are committed to meeting the health needs of persons with disabilities.

As suggested by the respondents in this study, this will entail sensitizing donors and increasing the visibility of disability as an issue worthy of more attention among humanitarian networks. While the EXCOM conclusions on displaced persons with disabilities (Executive Committee, 2010) represent an important first step in this direction, they must be followed by sustained advocacy and coordinated action.

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