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# 'The Highest Attainable Standard': The Right to Health for Refugees with Disabilities

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**Abstract:** The Convention on the Rights of Persons with Disabilities (CRPD) creates duties for States Parties and UN agencies to ensure that individuals under their protection have equal enjoyment of the full range of human rights. This includes the Article 25 right to enjoy 'the highest attainable standard of health without discrimination on the basis of disability.' However, refugees, who are forced to seek protection outside their state, face particular obstacles to maintaining an adequate level of wellbeing and accessing services to meet their health needs. Among this group, those who have a disability may confront multiple intersecting challenges. This paper draws on the findings of research across countries that play host to significant refugee populations. It explores the contribution of the CRPD to the international human rights framework for refugees, with particular attention to the right to health. Incorporating evidence from the field, it discusses the implementation of these rights and related duties in humanitarian responses across the world. This article discusses common barriers to health services for refugees with disabilities in six host countries. Based on the broad conceptualization of health and wellbeing established in the international legal framework, it also examines the relationship between the fulfilment of Article 25 and other basic socioeconomic rights. It provides examples of good practice and identifies strategies to better ensure the rights set out in Article 25 of the CRPD.

**Keywords:** CRPD, disability, migration, displacement, refugee, health, human rights, wellbeing, development

## 1. New Paradigms for the Right to Health

Disasters and forced displacement do not affect all persons equally. The very old and the very young and, indeed, women generally face heightened risks of harm (see, e.g., Neumayer and Plumper's study of disasters over 21 years [1]). However, research suggests that persons with disabilities are the most likely of all to suffer death, injury and disadvantage. For example, the earthquake and tsunami that struck in the Indian Ocean on 26 December 2004 killed over 230,000 people in 14 countries. It was reported that four times as many women died as men; that one-third of all fatalities were children; but that persons with disabilities fared worst [2].

Where people are displaced across borders as refugees—a term that has a distinct legal meaning but is often used to describe broad classes of involuntary migrants (see art 1A(2), Refugee Convention) [3,4]—the challenges facing those with disabilities are compounding. Refugees by definition have left their homelands in situations which mean that they cannot rely on their national government for assistance. They live in fear of the country from which they have fled.

At one level, the plight of persons with disabilities in displacement should be self-evident. Physical and other impairments will often make it more difficult for individuals to flee or to avoid harmful situations; and/or to access safety and relief opportunities. Yet, persons with disabilities for too long have been the 'forgotten and invisible' refugees [5]. The problem for host governments and for welfare agencies is that disability is not always easy to identify in large populations of displaced persons. While it may be easy to discern that an individual is completely blind or has lost a limb, there are many other physical and psychosocial impairments that are not so apparent. Cultural and other factors can also lead individuals to hide or deny disabilities. The very nature of forced displacement situations can also make it difficult to accommodate the needs of these refugees.

In this paper, we use the findings of fieldwork in six countries to explore the gulf that often exists between the lived experience of refugees with disabilities and the rights that they should enjoy under international law. We examine one of the oldest systems of human rights law—that devised for the protection of 'refugees'—along with newer international conventions. These create frameworks recognising a human right to health in all persons, including those with disabilities who find themselves in displacement.

As we examine in subsequent sections of this article, the right to health has long been recognised as a core tenet of human rights law. Moreover, the right to the 'highest attainable standard' of health is regarded as non-derogable. This means that states cannot deny their obligations when emergencies strike. The International Covenant on Economic, Social and Cultural Rights (ICESCR) [6] cannot be suspended in any circumstances. The rights to adequate food and water, shelter, health and medical services, clothing and sanitation and non-discrimination are enshrined there as 'survival' rights that underpin the very right to life [7–9].

For its part, the Refugee Convention was built on an understanding that displaced persons deserve protection in all circumstances—specifically when denied the natural protection of the state of either nationality or habitual residence [10]. In the context of humanitarian disasters, the United Nations High Commissioner for Refugees (UNHCR) often operates as a front-line relief agency. Either directly or through implementing partners, it provides shelter, medical care and food aid and acts as coordinating body for other UN and international aid bodies [5] (ch. 2.3).

In this part, Section 1 of our paper, we set the scene for our analysis by articulating the change in thinking that has occurred (and/or that needs to occur) around notions of health, disability and displacement. We also provide a brief overview of the fieldwork on which our observations are based. Thereafter, Section 2 examines the international legal framework for the right to health and includes an overview of how these apply in the six countries chosen for our study. How these rights translate in practice forms the focus of the longer and more finely grained analysis in Sections 3 and 4 of this article. In Section 3, we explain the methodology used in our research, before exploring the displacement contexts in each of the fieldwork locations. Section 4 is devoted to examining the available data on disability obtained through the fieldwork and complementary studies. We evaluate the health services available to refugees with disabilities in each country, examining both the structures supporting service delivery and the barriers to the realisation of health outcomes. Section 5 extends the examination to other basic rights which affect health, including access to food, water and sanitation, highlighting some of the key challenges for refugees with disabilities. This paper concludes in Section 6 with a summary of our findings and some reflections on how the right to health might be more inclusively promoted in displaced populations going forward.

### *1.1. Changing Global Approaches to Disability*

In 2011, the World Health Organisation (WHO) undertook a global survey that suggested that 2.9 percent of the world's total population comprise persons with severe disabilities, while a further 12.4 percent have moderate long-term disabilities [11] (p. 34) [12] (ch. 2). The WHO survey was undertaken in response to the conclusion of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and cannot properly be understood without considering this instrument [13,14]. At the centre of the CRPD is the notion that disability is a social construct reflecting the failure or inability to accommodate a person's impairment so as to allow full participation in society. Article 1 states that:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

This definition has been read to require states to look beyond a 'labelling' or medical approach to disability so as to examine the extent to which individuals are able to participate in real time. The CRPD demands that persons with disabilities be treated as rights-bearers rather than as 'objects of charity, medical treatment and social protection' (see statement by Louise Arbour, the UN High Commissioner for Human Rights, on the Ad Hoc Committee's adoption of the International Convention on the Rights of Persons with Disabilities, 5 December 2006, cited by Kayess and French, p. 11) [15]. The definition also requires states to adopt a capacities or functioning approach to the identification of disabilities. This is because Article 1 acknowledges that it is not impairment alone that makes a person disabled. Rather, it is impairment together with societal barriers (physical and otherwise) that lead to a person's inability to participate equally. This approach explains why the WHO found such a high rate of disabilities globally.

### *1.2. Current Approaches to Disability in Displacement*

Contrary to traditional assumptions that persons with disabilities cannot travel, our own and other recent research suggests that the WHO estimates are probably modest in refugee displacement contexts [12] (p. 8). In 2014, HelpAge International and Handicap International reported almost twice the WHO global average in the number of persons with disabilities fleeing the conflict in Syria. They found that 20 % of the surveyed population had a physical, sensory or intellectual impairment and one in seven had a chronic disease. One in twenty reported suffering from injury, with a majority of those injuries (nearly 80 %) resulting directly from the conflict [16]. In June 2018, UNHCR estimated that over 68.5 million people were on the move as refugees or forced migrants. Using WHO estimates, this could mean that there are over ten million refugees with disabilities across the globe [17].

The authors are part of a team which examined the situations of refugees with disabilities in six countries, in contexts that ranged from recent flight from 'hot' conflict (Syrian refugees in Jordan and Turkey); through long-term mass displacements in Pakistan and Uganda; to countries hosting a mix of long term and transit refugees (Malaysia and Indonesia). The project was conducted in close collaboration with the UN High Commissioner for Refugees (UNHCR) and its implementing and operational partners in the various countries, in recognition that UN agencies must respect international human rights treaties [5,18–23].

However necessary and admirable the various legal structures, the central problem with the system has been a tendency for agencies such as UNHCR to see their role as one of charity. The Refugee Convention does create important rights in refugees in some senses [24]. For example, it enumerates a set of 'welfare' rights refugees should have while in the host country, including the rights to rations (where applicable) (article 20), public relief and assistance (article 23), and social security (article 24(1)(b)) at the same level as 'accorded to nationals' and housing assistance 'not less favourable than that accorded to aliens' (article 21). However, the general emphasis in the instrument is on the obligations of states rather than on refugees as rights bearers. The touchstone article 33 non-refoulement duty, which requires states not to return refugees to the place where they face persecution, is an example in point. As we explore in Section 3, the traditional framework of the Refugee Convention and the tendency to see UNHCR as a relief agency has led to a tendency to conflate disability with medical issues. So it was in Malaysia that we found UNHCR using a database recording medical cases as the source of information on the incidence of disability within the population of concern in that region [21]. Such an approach to disability in displacement leads almost inevitably to failures to identify disabilities that do not present as medical emergencies and to focus on individual impairment rather than on the role that broader structures and contexts play in creating disability. In this article, we argue that the enjoyment of a right to health cannot be achieved without addressing such failures and looking beyond the provision of medical services.

## 2. The International Legal Framework for Health Rights [1]

Within the international legal framework, a number of key provisions demonstrate common understandings of health and wellbeing and affirm states' obligations to ensuring these rights for citizens and non-citizens alike. Below, we introduce and examine key provisions from the ICESCR and the CRPD to demonstrate the broad conceptualization of the right to health in international human rights law, and its emphasis on the equal enjoyment of this (and other) rights by *all people*, including refugees and persons with a disability. We then explain how these treaties and the Refugee Convention apply across each of the six countries included in our study.

### *2.1. The International Human Right to Health*

Article 12(1) of the ICESCR enshrines 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.' This right is without qualification, which means that it inheres in every person regardless of their nationality or immigration status. In this respect, the 1966 Covenant truly expressed the commitment that certain human rights be universal. Even so, the Covenant is not absolute in its proscriptions in circumstances where state parties are constrained by resource limitations or compromised security conditions. One of the remarkable features of the CRPD is that it expressly affirms the rights of persons with disabilities in all circumstances. Article 11 of the CRPD requires that States Parties:

> Take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

This confirms that rights like the ICESCR article 12 right to health apply even in emergency situations, or where individuals are forced to flee their countries.

Articles 25 and 26 of the CRPD adopt and reinforce the ICESCR provisions, affirming in all persons with disabilities the right to enjoy the highest attainable standard of physical and mental health.

The UN Committee that oversees the ICESCR (CESCR) has issued a general comment on Article 12 of that instrument which demonstrates the modern trend towards a capability approach to issues around the enjoyment of human rights [25,26]. The CESCR acknowledges that allowances must be made for both resource constraints and for the physical limitations inherent in certain disabilities: rights must reflect context. However, it calls on states to use measures to determine health outcomes that reflect actual access to goods, services and living conditions by each individual rather than broad statistics on health and use of medical services across a society [27] (para 9).

What is interesting about Article 12 of the ICESCR is that it sets a baseline for minimum acceptable standards of living in the area of health. It enshrines the right to access services necessary for maintaining or regaining health and includes a non-exhaustive list of measures states should support to help achieve this, focused mainly on the provision of health services and prevention of communicable and other diseases (see article 12(2)). However, importantly, the CESCR has also emphasised the connection between the realization of the right to health and other human rights, including:

> The rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement [27] (para 3).

The Committee reinforced this by explaining that:

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[1] This section of the paper draws on our work in Chapter 2. See 5. Crock, M.; Smith-Khan, L.; McCallum, R.; Saul, B. *The Legal Protection of Refugees with Disabilities: Forgotten and Invisible?*; Edward Elgar: Cheltenham, UK; Northampton, USA, 2017.

> The right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions and a healthy environment [27] (para 4. See also para 11. See also [28], article 11, which draws links between health and safe working environments).

There is an obvious connection between health and wellbeing and access to food, shelter and safety. We saw this in our research when examining the relationship between displacement and personal insecurity and the acquisition of disabilities. The research in Uganda uncovered a strong connection between experiences of sexual violence and disability [18]. Hunger and lack of shelter are natural breeding grounds for disease, harm, injury and even death [29] (p. 20, as cited in [24] (p. 508). It is for this reason that the rights to food, water, and housing must be considered as essential elements in the protection of health [24] (p. 508), [27] (para 44(b)). We discuss this in more detail below.

The CRPD deals at some length with the right to health. Article 25 affirms that persons with disabilities 'have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'. It echoes the ICESCR in stating that this right requires states to ensure equal access to medical services including reproductive health and population-based health programs; disability-specific health services, including early identification and intervention programs. It provides that health services not only be appropriate and adapted to individual disabilities but that they be accessible and physically proximate to the home or community of persons with disabilities. Prohibitions on discrimination require equal quality of care with a focus on patient autonomy and informed consent; and protections against the denial of treatment and restricted access to health insurance (CRPD, art 25(a)–(f)).

The CRPD goes further than the ICESCR in its acknowledgment that the equal treatment of persons with disabilities can require pro-active interventions to allow an individual to access basic services necessary for subsistence and full participation in society. For example, foundational articles 5 and 9, relating respectively to equality and accessibility emphasize the implementation of a variety of measures to overcome barriers to full participation and access. Article 5(3) of the Convention provides that '[i]n order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure reasonable accommodation is provided'. Article 9(2) enumerates specific measures that may need to be taken, from creating and policing accessibility standards for public and private entities (art 9(2)(a)–(b)) to promoting the creation of accessibility information and communication technology (art 9(2)(h)). Further, Article 26 states that States Parties must employ measures to assist persons with disabilities to:

> attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life (CRPD, art 26(1).

The obligation to design and implement habilitation and rehabilitation services for persons with disabilities includes services relevant to health care. The aim of these services is to allow persons born with disabilities to learn skills to facilitate their engagement and involvement in society, or where the disability is newly acquired, to restore capacity and assist individuals to readapt to society [30] (p. 78). The core principle that persons with disabilities be consulted in all matters concerning them is supposed to extend to the design of such services. This is one area in which we found very little evidence of states or relief agencies reaching out to refugees with disabilities in displacement. See Table 1.

**Table 1.** Human rights treaties—Relevant articles and their effects.

| Treaty and Article | Description |
|---|---|
| *Convention relating to the status of Refugees 1951* | |
| Article 1A(2) | Defines who is a refugee |
| Articles 20–24 | Basic welfare provisions covering refugees' access to rations, housing, public relief, and social security, etc. |
| Article 33 | Prohibits parties from returning refugees from the country they are fleeing |
| *International Covenant on Economic, Social and Cultural Rights 1966* | |
| Article 11 | Sets out rights to adequate standard of living (food, clothing and housing) |
| Article 12 | Sets out right to the 'highest attainable standard of health' |
| *Convention on the Rights of Persons with Disabilities 2006* | |
| Article 1 | Describes persons with disabilities |
| Article 5 | Requires parties to take measures to ensure equality and overcome discrimination |
| Article 9 | Sets out duties related to accessibility to ensure participation and full enjoyment of rights |
| Article 11 | Provides that Convention on the Rights of Persons with Disabilities (CRPD) applies in conflict/emergency situations |
| Article 25 | Echoes International Covenant on Economic, Social and Cultural Rights (ICESCR) article 12 right to health |
| Article 26 | Sets out right to habilitation and rehabilitation |

### 2.2. Human Rights Legal Frameworks in Six Refugee-Hosting Countries

Ratifying international human rights treaties is a matter of individual choice for each state, reflecting domestic political and/or international geopolitical strategy, meaning that many of the countries included in our research are not parties to the Refugee Convention. The exceptions are Uganda and Turkey, although the latter ratified the Convention with a geographic limitation, meaning it effectively excludes modern-day refugees. The remaining fieldwork countries are not signatories to the Convention or its 1967 Protocol. While not a party to the Convention, Jordan's constitution enshrines rights to protection for political refugees: article 21 states 'Political refugees shall not be extradited on account of their political beliefs or for their defence of liberty' [31]. However, all of the fieldwork countries have ratified the CRPD and all except Malaysia are parties to the International Covenant on Economic, Social and Cultural Rights (ICESCR). The complete details of the relevant ratifications are set out in Table 2, below.

**Table 2.** Human rights treaties and membership of case study countries (date of accession/ratification).

| Treaty | Malaysia | Indonesia | Pakistan | Uganda | Jordan | Turkey |
|---|---|---|---|---|---|---|
| **Refugee Convention and Protocol** | No | No | No | 27 September 1976 | No | 30 March 1962<br>31 July 1968 (with geographic limitations) |
| **CRPD** | 19 July 2010 | 30 November 2011 | 5 July 2011 | 25 September 2008 | 31 March 2008 | 28 September 2009 |
| **ICESCR** | No | 23 February 2006 | 17 April 2008 | 21 January 1987 | 28 May 1975 | 23 September 2003 |

While therefore, technically, the ICESCR is not binding on Malaysia, the fact that Malaysia has ratified the CRPD demonstrates a commitment and creates an obligation to ensure the highest attainable standard of health for persons with disabilities (under CRPD article 25). Further, the commentary from the CESCR, described above, still provides helpful insight into the way this right and related state obligations have been interpreted.

The legal framework described in this section is crucial to the analysis and arguments we make below. First, the right to the highest attainable standard of health (and related state duties) applies to all persons, regardless of citizenship or disability status. Second, states may need to undertake interventions to ensure that this right is equally practically accessible for all. Third, health is understood much more broadly than access to medical services: it depends on the fulfilment of a variety of basic human needs.

## 3. Rights in Reality: Disability and the Enjoyment of Health in Displacement Settings

Rather than creating new rights, the CRPD primarily seeks to ensure that the full range of human rights that should be available to all people are enjoyed on an equal basis by persons with disabilities, including those who have been forcibly displaced [32] (p. 13). Therefore, the emphasis is on examining real contexts and identifying areas where improvements are required. The remainder of this article draws on the findings of fieldwork across six different refugee-hosting locations, Malaysia, Indonesia, Uganda, Pakistan, Jordan and Turkey. After providing an overview of the project and the different displacement contexts included, we identify emerging themes relating to service access and more broadly the enjoyment of health and wellbeing for refugees with disabilities.

### *3.1. The Protection of Refugees with Disabilities Project*

The *Protection of Refugees with Disabilities* project was led by Professors Mary Crock, Ben Saul and Ron McCallum at the University of Sydney Law School and funded by a grant from the Australian Government's Department of Foreign Affairs and Trade, as part of a policy focus on improving disability inclusion in international development. Laura Smith-Khan participated as a full-time research assistant for the duration of the project. Fieldwork took place over three years, across six countries, commencing with Malaysia and Indonesia in 2012, Pakistan and Uganda in 2013, and Jordan and Turkey in 2014. The researchers spent between two and three weeks in each location. As with all research involving human participants, approval was obtained from the University's Human Ethics Research Committee. We interviewed representatives from UNHCR and other NGOs assisting refugees, as well as, where possible, relevant government officials.

We also conducted structured questionnaires to identify and explore the experiences of refugees with disabilities in Malaysia, Indonesia, Uganda and Jordan. The questionnaires collected basic demographic information, and included an initial open question, asking participants whether they had a disability and to describe it. It then went on to more specifically ask about functionality, in a set of questions inspired by those developed by the Washington Group on Disability Statistics, and based on the International Classification of Functioning.[2] This allowed us to explore and compare the self-reported experience of disability and individual conceptualization of disability with more specific self-reports of functioning (for more details see [19,21]). For each function, the questionnaire also asked what the participant needed to overcome any difficulty and whether these needs were being fulfilled. As we adopted a human rights-based approach to disability, we were interested not simply in identifying individual impairments or functional difficulties. We wanted to understand individual experience and how those who self-identified as having a disability or having functional difficulties actually fared in their day-to-day life. Therefore, the questionnaires (and other data collection) also explored access and participation across various aspects of life, the experience of pain, fatigue and disturbed affect and disability acquisition. In each location, these individual questionnaires were complemented with group discussions and home and neighbourhood visits. The questionnaire structure, and the inclusion and wording of questions was reviewed and revised after

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[2] More information about the group and the questions they developed is available on their website: http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/.

each field trip to best meet the needs of the research, in terms of saturation and the diversity of the displacement contexts.

Due to the spread-out nature of the urban refugee populations and the limited time researchers had to collect the data, the sample was purposive, rather than random, including research participants identified by key gatekeepers from NGOs and refugee community groups as either having a disability or serious health condition. This means that results do not produce generalizable statistics, but rather provide an opportunity to explore individual perceptions and conceptions of disability and compare these (and the type of disability data they elicited) with reports related to specific functioning, participation and unmet needs and other displacement experiences. In Malaysia and Indonesia, the questionnaires were conducted in person by the researchers with the assistance of interpreters. A total of 151 questionnaires were completed in Malaysia and a further 58 in Indonesia. In Uganda, questionnaires were conducted in two refugee settlements in the south of the country. Initially these were implemented in person by the researchers and interpreters, once again with the assistance of gatekeepers. However, the demand for participation increased rapidly as word spread about our research, leading the team to distribute photocopies of the questionnaire for self-completion in English or French. Refugee research assistants were also recruited to assist participants to complete the questionnaires where required. In total, just under 1000 questionnaires were collected. Finally, 11 participants were interviewed using the questionnaire in Jordan, most of whom were pre-identified as having a disability through an NGO gatekeeper.

In all countries except Pakistan, the team also conducted site visits to service providers, and places where refugees were living, including settlements, camps and homes in urban areas, and met and interviewed individual refugees and groups of refugees. We also identified and spoke with local Disabled Persons Organizations (DPOs) and local and international human rights bodies. In Pakistan, the researchers conducted interviews with UNHCR, and a senior government official responsible for Afghan refugees, and conducted a group discussion with a large group of DPOs and development NGOs. Following the fieldwork, we collaborated with UNHCR Pakistan to analyse data collected from a 2011 survey of almost one million Afghan refugees, which had used a similar functionality-based approach to identify disability in one section of the survey [33,34].

### *3.2. Displacement Contexts*

The fieldwork countries included in the study represent a range of forced migration contexts, allowing an exploration of the diversity of refugee experiences. A brief explanation of each context is set out below. Malaysia and Indonesia represent two countries that are generally regarded as transit locations for refugees, including those directly fleeing neighbouring nations in South-East and South Asia, and others coming from further afield, including the Middle East and Africa. Neither country is a party to the Refugee Convention, and very little is offered by way of official status or rights for refugees. This means that forced migrants in these countries risk and frequently spend time in immigration detention.

Despite a lack of formal domestic legal frameworks for refugees, UNHCR works in both locations, with some government cooperation. In Malaysia, a Joint Task Force with the government was established in 2016 to improve outcomes across a number of areas, including health. Further, improved collection of biometrics and issuing of identity cards has reportedly improved government recognition of UNHCR Refugee Status Determination (RSD) processes [35]. In Indonesia, the Presidential Regulation on the Handling of Refugees came into force in 2017 [34]. While the impact of this development is yet to be seen, the Regulation recognizes UNHCR, including in its definition of a ‘foreign refugee’ those who have been granted asylum seeker or refugee status by UNHCR (see article 1(1)). The Regulation also provides for coordination with UNHCR where persons intercepted by Indonesian authorities identify as refugees (art 13 (3)) [36].

In Malaysia, UNHCR assists over 150,000 persons of concern, with over 85 percent of this group coming from Myanmar [35]. Globally, it represents a major resettlement operation: 3290 refugees were permanently resettled to third countries with UNHCR’s assistance in 2017 [35]. In contrast, the number of persons assisted by UNHCR in Indonesia is much smaller. In 2017, UNHCR reported

13,840 persons of concern in the country, a slight decrease from the previous year, with Afghanistan the most common country of origin. A total of 760 persons were resettled out of Indonesia in 2017 [37]. Due to the limited opportunities for local integration in Malaysia and Indonesia, UNHCR has traditionally emphasised resettlement as the most suitable durable solution. However, recent policy changes in key resettling countries, such as the United States and Australia, have meant a dramatic drop in the numbers of resettlement places available, resulting in UNHCR's global resettlement submissions in 2017 (75,200) being less than half those made in 2016 (163,200) [37] (p. 9). This has meant that refugees are increasingly more likely to spend extended periods of time in Malaysia and Indonesia. This makes it even more essential that the many barriers to economic and social participation and the enjoyment of basic human rights, including health rights, are addressed.

Pakistan and Uganda both have long histories of hosting large numbers of refugees from neighbouring countries for protracted periods. While not a party to the Refugee Convention, Pakistan has hosted and registered millions of Afghan refugees over the past decades, with much smaller numbers of refugees from other countries receiving support and status determination directly from UNHCR [34,38]. In 2017, UNHCR identified close to 1.4 million refugees and asylum seekers in Pakistan [38]. Refugees in Pakistan live in various locations throughout the country, in urban centres, rural areas and in and around 'refugee villages' which provide some extra support [34,39]. Refugees in Uganda similarly live throughout the country, including as urban refugees in cities and towns, or in 'refugee settlements': land allocated and controlled by the Ugandan government, in which various NGOs provide services and refugees are allotted small plots of land on which to live. In 2017, Uganda was also found to be hosting just under 1.4 million refugees and asylum seekers [38], with arrivals continuing from the neighbouring countries of South Sudan, the Democratic Republic of Congo (DRC) and Burundi throughout 2018 [40].

Jordan and Turkey continue to host large numbers of people fleeing the ongoing conflict in Syria. According to UNHCR statistics, there were 3.6 million Syrians in Turkey in September 2018 [41]. While UNHCR had over 734,000 registered people of concern in Jordan in 2017, Jordanian officials generally cite significantly higher figures, surpassing one million people [5] (p. 58). The situation has now transitioned from one focusing on the reception of emergency influxes, to longer-term planning, with an emphasis on improving, through legislation and practice, the inclusion of Syrian refugees in education and employment.

## 4. Access to Health Services: Country Comparisons

In the fieldwork, discussions of disability amongst refugees were often closely linked with access to health and medical services. Conducting our research, we were frequently referred to officers or representatives who were responsible for health issues. Lists of persons identified as having a disability were normally collected in the context of assessing or assisting persons with specific need of medical treatment of some kind. This undoubtedly assisted in identifying persons with a range of impairments, who were indeed often experiencing disability. However, this conflation of medical need and disability meant that the actual experience of disability and the contextual and structural issues responsible for it, were often invisible. On an organizational level, this demonstrates a serious challenge for effective program design, and indicates the lingering influence of the medical model of disability in humanitarian contexts. In practice, we found in our research that focusing on impairments meant that those with a recorded disability often only had their most obvious impairment identified and mentioned. This means that other impairments or health needs not obviously connected to the key identified impairment may go overlooked altogether. This was the case for the very first research participant we met in Malaysia, who used a wheelchair, but had a previously unidentified vision impairment; or the widespread experience of unaddressed psychosocial difficulties, reported across all the fieldwork locations.

While discussion around health in the context of disability should therefore be approached with these conceptual challenges in mind, access to health services remains a serious issue for many refugees, and those with a disability often face a range of additional barriers. Common types of barriers have been categorised in Table 3, below. An explanation of the overall challenges related to each type of barrier is included, along with additional barriers for persons with disabilities. These examples, and the more detailed discussion in the sub-sections below, demonstrate the interconnectedness of these barriers. For example, the adequacy of services and their affordability are interrelated: free services may not respond to all needs, making them inadequate. Likewise, some services may be available locally, but specialist services or free/affordable services may require substantial travel. Similarly, communication/information barriers may also create misunderstandings about the cost, location, availability and/or adequacy of services.

**Table 3.** Common barriers to accessing health services for refugees and additional barriers for persons with disabilities.

| Barrier | Overall Challenges | Additional Barriers |
|---|---|---|
| Affordability | Most commonly identified barrier. Refugee incomes are often well below national poverty lines. In some locations, compounded by limited access to public health services due to non-citizen status, or the unavailability of free specialist care. | Persons with disabilities commonly have less household disposable income.<br>Costs compounded by limited transport options.<br>Assistive devices are not provided, even where diagnosis is available (e.g., glasses).<br>Specialist services are less likely to be free. |
| Bureaucratic | Prioritization of 'urgent' treatable needs over long-term care.<br>Difficult to obtain travel clearance or access services outside assigned area based on registered address.<br>Age-based inclusion criteria problematic in forced migration. | Persons with disabilities that are not 'curable' or who need ongoing support, e.g., with pain management, may quickly exhaust their allocated assistance.<br>Fear around the impact of disclosing disability to refugee agency on refugee status determination and resettlement outcomes. |
| Demand/ resources | Public/NGO services are overburdened and cannot meet demand. | Persons with disabilities pushed to the back of queues, experience distress or discomfort over waiting times. Overreliance on private/high fee services.<br>Competition/limited places available for specialist/secondary services. |
| Geographic/physical | Affordable and/or specialist services are located far from refugee housing. | Limited accessible transport options.<br>Requiring the assistance of a friend/family member to navigate to/access the service.<br>Physical accessibility of buildings: e.g., stairs, inaccessible toilets, etc. |
| Communication | Language barriers between refugees and service providers may impede access to, or limit information about, available services. | Information for refugees may not be shared in accessible formats, and appropriate interpreting assistance is less likely to be available in non-local sign languages<br>Increased risk of social isolation decreases access to information. |
| Social/cultural | Stigma attached to certain conditions or experiences: e.g., accessing reproductive services for pregnancy/birth or injury resulting from sexual violence.<br>Ethnic, religious, age- or nationality-based discrimination. | Specific impairments/disabilities attract direct discrimination from the community, family or health service providers and deter disclosure/encourage social isolation. |

The six fieldwork countries presented a variety of circumstances and approaches that resulted in a diversity of experiences in terms of access to health services. In the section that follows, our research findings, along with data from other studies and surveys are used to elucidate key concerns in each location and highlight positive responses to address these interconnected existing barriers.

## *4.1. Malaysia and Indonesia*

### 4.1.1. Health and Disability Overview

Given the limited rights and lack of state recognition of urban refugees in Malaysia and Indonesia, there is generally a heavy dependency on UNHCR and other international and local NGOs to provide assistance in a range of areas, including health. While free clinics operate to assist refugees with basic primary health needs, those with more complex or ongoing needs are more likely to rely on the financial and sometimes logistical assistance of UNHCR or the International Organization for Migration (IOM) (in Indonesia). In Malaysia, major concerns include the spread of communicable diseases, especially multi-drug resistant forms of tuberculosis, due at least in part to the cramped and poorly ventilated living conditions, and conditions in immigration detention facilities [42].

Among questionnaire participants in Malaysia, over 60 percent reported issues with mobility, over 45 percent had difficulties with self-care and over 40 percent reported vision difficulties. About 45 percent had cognitive difficulties. In Indonesia, participants reported functional difficulties following a similar pattern, with mobility-related difficulties again being the most common (just over 40 percent), followed by cognitive difficulties (31 percent) and vision difficulties (26 percent).

For those who reported acquiring a disability after their arrival in the host country, accidents were the most common cause in Malaysia (15 out of 48 people), followed by disease (12 reports). Accidents commonly involved workplace safety issues, and road injuries. Participants reported sustaining serious permanent injuries or chronic illness while working, for example in plantations outside Kuala Lumpur or in automotive jobs where they were exposed to dangerous chemicals. In Indonesia, accidents were the second most common cause of disability acquisition (5 out of 15) and most often related to attempted escapes from immigration detention. Disability acquisition was most commonly attributed to stress related to the lived experience of displacement (8 out of 15 participants). In Indonesia, participants cited specific trauma related to detention (a number of participants in Malaysia also presented with serious physical injuries from detention), as well as the ongoing uncertainty of the disproportionately slow registration, status determination and resettlement assessment processes.

Without systematically asking participants in Malaysia about pain, the research uncovered a significant proportion (65 of 151 participants) reporting that they experienced pain related to their disability or health condition. Of these, 28 persons reported having insufficient access to pain relief, understandably affecting their well-being on an ongoing basis. Consequently, questions related to pain (as well as affect and fatigue) were integrated and explored systematically for the remainder of the fieldwork. Likewise, while data relating to affect were not gathered systematically, interviews with refugees and key gatekeepers identified this as an important issue and one presenting significant challenges. In Indonesia, a third of participants reported experiencing pain and/or fatigue at least most days, and 41 percent reported disturbed affect (anxiety or depression) every day. Of those experiencing pain, almost half (16 of 37) reported having insufficient pain relief.

In Malaysia, of the 62 participants who reported having difficulties with their vision, 56 said that they had outstanding assistance needs. Similarly, in Indonesia, of the 13 persons needing assistance with their vision, nine reported not having enough help. The divide between the availability of a diagnosis and provision of assistance was apparent here: research gatekeepers in Malaysia explained that service providers had carried out eye tests for large groups of the refugee community and given individual diagnoses, but there was no follow-up provision of glasses where required, and individuals often lacked the funds to buy their own.

#### 4.1.2. Barriers

In Malaysia, a significant number of participants reported facing barriers to accessing any medical treatment at all (53 out of 151 participants). For this group, the most commonly reported barriers were financial: 44 participants said that they were unable to access medical assistance due to being unable to afford the required fees. A further eight identified the cost of transport or distance to relevant services as the largest barrier they faced. The remaining individual was unsure how to access services or what services existed that could assist them. More recently, UNHCR Malaysia itself has identified low income, transport accessibility and the location of services as ongoing key issues to health care access [43].

These types of accessibility issues were acknowledged by UNHCR and addressed in part through the operation of mobile health units, travelling to assist refugees living and working in areas outside Kuala Lumpur. Further, the refugee community groups which are well established, such as those from various minority ethnic groups from Myanmar, provide some basic services in their community centres. These groups create an important channel for the identification of health needs amongst the communities they serve. However, these centres are often located on the higher levels of old apartment buildings, presenting obvious physical accessibility issues. The findings of the research also suggest that persons with disabilities are more likely to be socially isolated, find it more difficult to leave their homes and travel to these centres, or find out about or communicate with community leaders. This is exacerbated for refugees who do not have well-established communities in Malaysia, such as those coming from the Middle East and Africa. Another alternative was for NGOs to provide (or cover the cost of) accessible transportation for individuals to access specialist treatment. This was the approach in Indonesia, for example, for refugees registered with the International Organization for Migration (IOM). However, this option obviously entails significant cost and is only possible in settings where support is offered to small numbers of people.

While NGOs provide some free assistance to refugees, their limited funding means that they often have limited human resources, leading to long wait times, and limited material resources to sufficiently respond to needs. Participants in Malaysia explained that the overcrowded nature of the free clinics meant that they would sometimes have to wait a whole day in discomfort or pain, only to be told they would have to come back the following day. Being constrained to accessing alternative private clinics closer to home, with lower wait times meant incurring substantially higher costs than others who could access cheaper transport options and better manage the long wait times.

Beyond the financial impact of limited work rights, immigration status and host country policies can impact access to health in a variety of ways. At the time of our fieldwork, refugees in Malaysia, as non-citizens, had to pay substantially higher rates than locals to access the public health system. In Indonesia, IOM is the main provider of humanitarian assistance for refugees and while there are a few other NGOs assisting refugees, those registered with IOM generally have access to a comparatively high level of housing and financial assistance. However, in order to be registered with IOM, refugees first must come into contact with Indonesian immigration authorities and almost always have to spend a significant period of time in immigration detention before being referred to IOM, creating serious risks for their physical and mental wellbeing. Relative to Malaysia, informal employment opportunities in Indonesia are very limited, making NGO support essential for anyone without substantial personal savings. For example, a single mother with three children explained to us that her situation was so dire that she had been regularly waiting outside the gates of a detention facility, in the hope of being detained, so as to access IOM support. Similar reports have been identified in other research [44]. Asylum seekers who have not been processed by UNHCR face even further marginalization, with very limited access to any NGO support at all.

In line with the need to ensure health care is free or affordable, a major recent development in Malaysia has been the establishment of a private health insurance scheme for refugees, making a wider range of public and private health services more accessible. Known as REMEDI, the new scheme for refugees has been predicted to improve health care access, but enrolment rates remain low: only just over 23,000 individuals have been enrolled to date, and in 2017 only 402 accessed care using the scheme [43]. More time is needed to measure the success of the scheme and identify any ongoing barriers for refugees who have a disability.

### *4.2. Pakistan*

#### 4.2.1. Health and Disability Overview

Due to the protracted, sometimes multi-generational, nature of Afghan displacement in Pakistan, most refugees are expected to live self-sufficiently. Officials there suggested that the most socioeconomically vulnerable tend to live in proximity to the refugee 'villages', (approximately 40 percent of the total Afghan refugee population) so as to access the NGO services provided there [34,39]. Potentially connected with this, the survey revealed that those who reported functional difficulties were more likely to live in a refugee village than those with no functional difficulties: 54.3 vs. 50.1 percent respectively [34] (p. 37).

Refugees living in the host community in rural or urban areas are expected to access the same health care services as Pakistani nationals. Health services are one important component of the assistance UNHCR provides to those living in refugee villages, with approximately 62 low-fee Basic Health Units funded by UNHCR and run by its implementing partners in villages across the country, targeting primary health care, reproductive health, immunization and treatment of key communicable diseases. However, a decrease in funding and a decrease in visitor numbers means the sustainability and utility of separate village-based services are being questioned. Recent strategies prioritize 'community-based' services, with an emphasis on refugee community capacity building, improving collaboration and partnerships with local health services and facilitating equal access for refugees, including marginalised groups. UNHCR also reports exploring the possibility of establishing an insurance scheme for refugees similar to the one now operating in Malaysia [39].

Analysis of data from the census-like survey conducted by UNHCR and the Pakistani Government reaching almost one million Afghans in Pakistan [33] revealed that close to 8.2 percent of the surveyed population have at least one functional difficulty, in line with global estimates (see [36] for more details regarding the statistics in this section). Of that group, difficulties with sight were most common (affecting almost 5 percent of the total population, and 58 percent of persons with functional difficulties). Of those reporting functional difficulties, almost 40 percent had multiple difficulties.

A significant gender division exists, with disability prevalence substantially higher amongst adult women than adult men. Further, women appear to be dying younger. This is reflected in the male-to-female ratio across different age groups: the ratio is at parity at 15 to 24 years of age but increases to 140 men for every 100 women for those 60 years and above.

Age also increases risk of functional difficulty, with reported levels well above global estimates for low-income countries: amongst people 60 years or above, disability prevalence amongst Afghan refugees in Pakistan is 46.6 percent, compared with 43.3 percent in developing countries worldwide [12] (see p. 27 for comparisons). The survey also uncovered a correlation between illness and functionality, with almost a third of persons who had a chronic disease also reporting a functional difficulty.

#### 4.2.2. Barriers

Significant barriers exist to accessing health services in Pakistan, for both refugees and Pakistanis with limited financial means. This is reflected in poor health outcomes relative to other countries in the region, including high infant mortality, prevalence of and lack of effective treatment for communicable diseases, polio and tuberculosis and, increasingly, non-communicable diseases [39]. The gravity of these challenges is reflected in the multiple international development agencies implementing health-focused projects in the country.

On top of these widespread challenges, people with disabilities in Pakistan face a number of potential additional barriers to accessing health care services. Once again, these include issues around affordability—especially for specialist care, lack of standardised disability data (or collection systems) to inform service design (an issue we identified across many of the fieldwork locations), inaccessible buildings, transport and location of required services, lack of infrastructure and human resources (across both primary and specialist care), stigma and discrimination and lack of sensitisation training, a lack of accessible information about available services, and a lack of referral systems and disability case management programs [45].

The design of the questioning in the survey made it difficult to ascertain whether reported assistance needs were met or unmet. However, in line with reporting on functional difficulties, the most commonly reported assistance need was the provision of 'reading glasses', with 15.9 percent of those with a functional difficulty identifying this as their main need. The next most common assistance type was financial support (9.7 percent), reflecting the connection between functionality, inclusion and socioeconomic status. The ambiguity of the data elicited in this section of the survey raises a central issue identified across the literature on disability inclusion and an argument we have made elsewhere: a lack of clear data about key barriers undermines the design and ultimately the accessibility of services [21].

## *4.3. Uganda*

### 4.3.1. Health and Disability Overview

While the questionnaire in Uganda was effectively opened up to anyone who collected and completed a copy across the two refugee settlements where it was implemented, a vast majority of participants (893 out of 970) identified at least one functional difficulty. Similar to other fieldwork locations, questionnaire participants most frequently identified issues with vision and mobility (63 and 62 percent), followed by cognition (almost 58 percent). Significantly, almost half (49 percent) of the participants reported experiencing pain every day. Many attributed their pain to an impairment or injury that had been inadequately addressed, for example bullet wounds or injuries from sexual violence that had not be treated. Others explained how their living and work conditions exacerbated this. Disturbed affect amongst participants was also very common, with 57 percent reporting experiencing anxiety, depression or nervousness most days or every day. The main causes were connected to participants' trauma from experiences before fleeing, or the exclusion they faced as a person with a disability. Fatigue was similarly common, with participants often drawing a connection between this and the pain and/or affect they experienced, or more generally with difficult work and living conditions.

In Uganda, attacks or violence were by far the most commonly identified cause for disability acquisition (just over half of participants). This led to sexual violence emerging as a key issue amongst the group, with 238 reports elicited without the questionnaire specifically probing for this. Between 10 and 15 percent of these reports involved sexual violence that had occurred while in Uganda. These reports were linked to a broad range of functional difficulties, infection and disease, as well as psychosocial issues and discrimination, all of which impacted inclusion and overall wellbeing. A further 270 participants identified disease or illness as key causes of their disability acquisition, including some that may also be related to violence, such as the contraction of HIV.

### 4.3.2. Barriers

While health and rehabilitation have been a focus area in recent activities targeting the inclusion of refugees with disabilities in Uganda, a number of serious challenges nonetheless emerged from the research in relation to health care access. First, while basic primary health care was available, specialist health care, rehabilitation services and pain management were clearly lacking.

In particular, psychosocial support services were inadequate, especially given the high prevalence of trauma and issues with affect reported by research participants. In the whole of Nakivale refugee settlement, UNHCR noted that there was only one psychiatric nurse, for a population of over 60,000 people. Still, we noted efforts to address this need, for example in the form of NGOs supporting the establishment of self-help groups of survivors, which can assist in addressing not only psychological issues but also help to raise awareness and combat social stigma and discrimination.

Once again, the location of specialist services in relation to refugee settlements presented a serious challenge for people with disabilities, who often lacked the financial means to travel for appointments or follow-up, and faced bureaucratic barriers, such as requiring official referrals and government permission to travel outside the settlements. This demonstrates one way in which limiting the right to freedom of movement can impede wellbeing. The physical accessibility of buildings, and infrastructure like roads, in rural areas but equally in the capital, Kampala, is notably poor, creating substantial barriers for those who manage to reach them in the first place.[3]

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[3] See for example the extensive work in this area by Uganda National Action on Physical Disability https://unapd.org/about-us/.

Various types of perceived or actual discrimination presented serious barriers for some refugees with a disability. Refugees in the settlements we visited spoke of their belief that their local Ugandan neighbours, who often faced similar levels of socioeconomic disadvantage, received priority when seeking medical assistance at primary health clinics. They claimed that this deterred them from seeking assistance, or meant that when they did, they had to wait longer or had less access to the required medicine. Similarly, an elderly participant with a disability expressed his concern with the lack of ongoing support for his chronic pain. He claimed that his age and the fact that his condition was not curable or temporary meant that he was not given sufficient ongoing pain medication.

Discrimination was also attached to specific conditions or their causes. This was the case for particular psychological and neurological conditions, such as epilepsy, where individuals were accused of being affected by witchcraft and risked physical harm when attempting to access services in public areas. Similarly, those who had experienced sexual violence were at times deterred from seeking medical assistance because of the need to disclose their experiences, and risking discrimination or reprisals.

However, despite facing relatively great challenges in terms of access to material assistance and serious strains on resources, some refugees with disabilities in Uganda benefited from the support of NGOs that provided empowerment activities and assisted them to self-organize into associations of persons with disabilities. In this way they supported the creation of environments in which refugees with disabilities could regularly meet, share their experiences and concerns and consult on the design of both mainstream and targeted programs (see [5,18]).

## *4.4. Jordan and Turkey*

### 4.4.1. Health and Disability Overview

The research in Jordan and Turkey focused on the Syrian crisis and its transition from an emergency to a more protracted displacement situation. Reports from local authorities and NGO representatives in both settings often emphasized impairments emerging from conflict-related injury. Although Syrian refugees generally have access to the national health systems, research participants shared their concerns about the burden created on existing facilities related to the large number of refugees needing urgent surgical and other medical interventions.

While our own questionnaire data were very limited in these locations, a survey in Jordan in 2017, targeting a random sample of over one thousand Syrian households in two camps and one urban location and using Washington Group question sets, identified a disability prevalence of 22.9 percent [46]. Many households experienced disability, with 62 percent of the sample having at least one member with a disability. The most common cause of functional difficulties was reported as being illness or disease (almost 30 percent). Similarly, an earlier study of Syrians carried out in Jordan and Lebanon shortly prior to our fieldwork highlighted the issue of untreated chronic disease and identified an overlap between those who reported having a chronic disease and who also had an impairment [16]. However, acquisition varied based on gender, with females more likely to attribute their difficulties to illness, and males more likely to identify injury [46]. While mobility-related difficulties were the most common amongst adults overall (14.4 percent), mental health, communication and behavioural issues were the most common amongst children [46]. Further, in Zaatari camp specifically, anxiety was the leading area of difficulty even among adults, affecting 15 percent of those surveyed, as well as almost 20 percent of children between 5 and 17 years [46]. This aligns with our interviews with service providers in both Jordan and Turkey, who also identified trauma, anxiety and depression as major issues, especially among children.

### 4.4.2. Barriers

Once again, the fieldwork uncovered additional barriers to health care for refugees with disabilities. Our findings largely aligned with those of the 2017 survey in Jordan, which reported that while households with a disabled member were more likely to require health care services than those with no disabled member (89.6 vs. 82.0 percent), they were less likely to have access to the services they needed (11.8 vs. 7.2 percent respectively) [46] p. 42. The survey found that for households with a disabled family member, the most common barriers identified were that the required service was not available, the service was too expensive or the transport to reach it was too expensive. This differed from households with no disabled family members specifically with regards to transportation, which was not as common an issue amongst the latter group.

Our research participants who reported mobility difficulties explained how difficult they found it to find and/or pay for accessible transport to take them to health services. In Jordan, for example, participants explained that taxis or busses would see them and keep driving.

In Jordan, the strict rules around gaining 'bail' and being authorised to leave a refugee camp and live in an urban area, and the registration of urban refugees in a given locality may act to restrict access to basic services. If refugees leave a camp without authorization or are obliged to move from one urban location to another—a common experience amongst participants who faced increasing difficulties to pay their rent—they may have to travel long distances to access the registered local health provider authorized to assist them. The transport-related challenges discussed above are thus further exacerbated in such cases.[4]

The financial difficulties connected with ongoing displacement and limited access to work rights means that even those refugees who initially may have substantial savings, as was the case for some of those who we met in Jordan and Turkey, find their financial resources rapidly diminishing. For example, in Jordan, UNHCR reports that over 85% of Syrian households now live under the poverty line [47].

The divide between camp and urban refugee settings also presents a complex set of conditions and considerations for refugees with disabilities. On the one hand, it is apparent that camps may present an excellent setting for providing a wide range of services for groups of refugees, all within a close distance to their target users, as was the case for refugee villages in Pakistan, as discussed above. A developing focus on improving inclusion was evident in the more recent camp-based operations in Jordan and Turkey: government official and representatives from humanitarian organisations in recently established camps we visited proudly showed us high-quality facilities, including a state-of-the art, brand new Red Cross hospital in the Azraq camp, complete with ramped entrances and a collection of wheelchairs. Similarly, in Turkey, camp officials explained that refugees with physical impairments were prioritised for housing that contained private internal bathrooms (unlike other housing which had shared bathroom facilities). The camp was flat and paved throughout, unlike the rocky and hilly refugee settlements in Uganda.

Still, the 2017 survey found that participants in camps often reported not being able to find the type of service they needed, meaning that they would have to try to leave the camp to access it. Further, while camps may be attractive for those who are socioeconomically vulnerable, they may also present dangers to families with a disabled family member. In Jordan, a family with multiple members with disabilities reported arriving in the Zaatari camp only to be warned to leave immediately if they wanted to remain safe. Similarly, despite its state-of-the-art facilities, officials in the then recently established Azraq camp explained they were finding it difficult to transfer refugees there as it was located in such a remote location, far from any surrounding towns or cities.

Access to habilitation and rehabilitation or any more complex assistance also varied in its availability. Aside from a lack of resources amongst NGOs, age-based policies also created problems. For instance, in Jordan, school-based programs open to refugees sometimes presented difficulties as they are designed for citizens who are born and attend school at expected, standard ages. For example, some programs were age-limited, available only to those under 18, or were designed with the expectation that children commenced them at the beginning of their schooling. This creates obvious barriers for forced migrants whose education may have been disrupted, or who at the very least are not of school-commencing age.

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[4] For an extended discussion of the combined impact of migration status and other personal attributes, see Chapter 6, 5. Crock, M.; Smith-Khan, L.; McCallum, R.; Saul, B. *The Legal Protection of Refugees with Disabilities: Forgotten and Invisible?*; Edward Elgar: Cheltenham, UK; Northampton, USA, 2017.

As in the other fieldwork locations, and in line with the 2017 survey, needs related to mental health were reported as being both the most prevalent and hardest to address. The service providers we interviewed (see for, e.g., our discussion in [5,18]) highlighted the cross-cultural and linguistic challenges connected with providing assistance. As in other locations, stressors related to the displacement context acted to create or exacerbate mental health issues, demonstrating the connection between environmental factors, social participation and mental health.[5]

Communication barriers were a significant concern also, echoing the findings of the 2017 survey in which 15.8 percent of households with a disabled family member cited this as a main barrier to accessing health care (vs. 7.7 percent in other households) [46] (p.43). Our discussions with officials regarding this potential barrier sometimes demonstrated a lack of appreciation for the risks or deterrents individuals may face when deciding whether to seek assistance. For example, in Turkey, when camp officials were asked how deaf refugees could approach them with any health or safety concerns, they suggested that it was fine for their relatives or friends to communicate with officials on their behalf. This approach presents some obvious and serious protection issues and contradicts UNHCR guidance that mandates the provision of impartial, professional interpreters wherever possible, and particularly warns against the use of family members as interpreters (p. 5) [49]. While it is understandable that it may be difficult to find Arabic Sign Language interpreters in Turkey, this level of isolation there and in other refugee-hosting situations could be addressed with the assistance of the local deaf community. For example, in Finland, local deaf volunteers have been identified as valuable agents in enhancing the participation of deaf asylum seekers, greatly increasing their ability to access information and seek support and decreasing their feelings of isolation [50].

Where organizations made an effort to include and empower persons with disabilities, the results were notable. Participants in Jordan explained how they felt reluctant to approach many of the service providers for fear that they would face discrimination or misunderstanding. However, they identified Handicap International (now called Humanity and Inclusion) as an exception: a place where they felt accommodated and where they would not need to explain themselves, making them more confident to seek assistance.

## 5. Beyond Medical Assistance: Disability and Wellbeing in Displacement

As discussed in Section 2 of this article, the international human right to health and wellbeing envisages much more than being able to access medical services. It requires acceptable housing, access to clean water and sanitation, adequate nutrition and basic personal safety. The socio-economic and legal status-related vulnerability of refugees across the fieldwork countries leads to a number of health-related risks beyond health care restrictions, ranging from the inability to access adequate nourishment, to being exposed to injury in informal employment, immigration detention, or in targeted interpersonal violence [51].

The type of informal work, such as exploitative labour, domestic or hospitality roles, most commonly available to refugees also often excludes people with disabilities, increasing the risk of socioeconomic vulnerability. Alternatively, or additionally, this type of work exposes refugees to the risk of acquiring impairments or serious health problems, such as was the case for some research participants in Malaysia. Refugee status and the lack of rights to safe and dignified employment therefore often contribute to creating socioeconomic vulnerability, as well as exposing refugees to an increased risk of acquiring an impairment. This vulnerability creates obvious difficulties for accessing health services, aligning with the above discussion: less disposable income means fewer options and opportunities to seek medical assistance, habilitation or rehabilitation, especially when these are located at a distance, or require payment of high fees, major barriers highlighted above.

Given these risks, it is therefore perhaps unsurprising that in many places, access to adequate water and nourishment can be serious problems for *all refugees*. In Uganda, conditions were particularly challenging and continue to be so. For example, in November 2018 alone, UNHCR

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[5] For a depiction of the connections between stressors, needs and experiences among Syrians in Jordan, see ref [48].

reported that over 800 children under the age of five years were treated for either Moderate Acute or Severe Acute Malnutrition in health facilities targeting refugees (these figures include a small number of local children: [40]).

Government bodies and NGOs assisting refugees adopt a range of strategies to address these challenges. In some situations, this involves providing material support in the form of food parcels, especially in camps or camp-like settings, such as the refugee settlements in Uganda. In Indonesia, refugees under the care of UNHCR or IOM receive monthly cash payments. In Jordan and Turkey, financial assistance has been provided through pre-paid bank cards, giving its beneficiaries greater freedom to choose how it is used. In Pakistan, Uganda, Jordan and Turkey, recent government efforts to extend some legal work rights to refugees will also hopefully help to increase self-reliance (see discussion in [5] (ch. 10)).

In some cases, the level of individual assistance may be set according to need or vulnerability. For example, in Jordan, UNHCR and its partners have developed a complex evaluation process through a Vulnerability Assessment Framework, although some challenges still remain for ensuring disability is explored and evaluated comprehensively [5,19,52]. Temporary financial assistance was also provided to some refugees with disabilities identified in Malaysia at the time of our fieldwork. However, in general, the amounts provided were small, and given for a set and short period of time, rather than on an ongoing basis. This usually aligned with a particular medical event, with the understanding that the short-term financial support would help the individual or family to pass through the period of recovery or access a particular medical intervention. While limiting financial support in this way is undoubtedly connected to serious budget constraints, unsurprisingly this approach proved ineffective for persons with disabilities whose opportunities to gain an income remained problematic more permanently.

Further, while financial assistance is useful, barriers in terms of housing and location of shops and other services may mean that refugees with disabilities incur greater costs to access food and water than other people. For example, in Jordan—one of the most water-poor countries in the world—refugee families reported having to buy potable water outside the home. The poor physical accessibility of affordable accommodation and limited accessible transport options meant that those with mobility difficulties often incurred additional costs to have water delivered to their home. Similarly, in Pakistan, only 55.9 percent of refugees with mobility difficulties reported having a water source within their home or compound, meaning that a significant number must either rely on others to collect their water, or else—where possible—pay for its delivery [39]. This is expensive, creating greater risk of inadequate access to clean water, or else decreasing the budget remaining for other essential needs.

Access to clean water is likewise a serious concern in Uganda, both in settlements and urban locations. Refugees living in refugee settlements reported a vast array of challenges when attempting to collect water from pumps and taps in central locations in the settlements. Aside from the lack of suitable transport to reach water and food collection points, research participants described how they struggled in crowded queues (limits on water meant that the taps/pumps only provided water at set times during the day). Some reported being physically unable to wait or unable to fill and lift their water containers, being pushed to the back of queues, or facing discrimination in the form of physical or verbal abuse. They faced similar challenges at food distribution points. The sometimes very significant distances to these facilities and the vast and isolated nature of the settlements also creates vulnerability to physical or sexual violence [18].

Aside from being crucial for sustaining human life, access to water is also essential for personal hygiene and thus health. Refugees with disabilities across the fieldwork countries commonly faced challenges in accessing suitable toilet and bathing facilities. In Uganda, pit-style composting toilets were common and presented obvious challenges to people with mobility difficulties. In Pakistan, persons reporting functional difficulties were slightly more likely to have access to a more sophisticated style of toilet (e.g., 13.8 percent reported having access to a flush latrine). Still, of those with mobility difficulties, over 20 percent had to use either an open pit or had no toilet at all [34]. This creates obvious serious health risks. Similarly, washing facilities were often inaccessible, restricting access to basic hygiene. The family of one participant in Jordan reported that they had to wash him in their kitchen because he was unable to access their apartment's bathroom. Such situations not only present risks to the physical wellbeing of the individuals involved. They also undermine their independence and dignity, with implications for their (and, at times, their family's) psychosocial wellbeing.

At least in camp settings, more recent operations demonstrate an increased awareness of the need to improve physical accessibility. Camps in both Jordan and Turkey included (some) accessible toilet facilities or gave priority to persons with disabilities for accommodation that included internal (rather than communal) bathroom facilities, as discussed in the previous section. Other strategies involved delivering food and water to persons with disabilities (we came across one example of this in Uganda), or nominating a 'collector' (usually a friend or relative) authorized to travel to a collection point and receive material assistance on behalf of the beneficiary, as was the case in Zaatari camp in Jordan. While the latter may help increase the likelihood of individuals receiving assistance, NGO representatives were cognisant that it was not a perfect solution. Relying on other persons to collect and deliver goods undermines independence, creating (or reinforcing) power imbalances, making it far from an ideal, fail-safe option [5] (ch. 9).

## 6. The Highest Attainable Standard? Concluding Reflections on Promoting Article 25 and Beyond

As we have tried to show, health involves much more than having access to a hospital or doctor. It is a state of mind and body that depends on an individual being furnished with adequate food, hydration, sanitation, clothing, shelter and basic security. None of these things are necessarily 'given' when people are forced to leave their homes and countries as refugees. Where refugees travel with or acquire a disability, the building blocks so crucial to human health and wellbeing can be elusive indeed. The significance of the more recent human rights conventions such as the CRPD is that they underscore the fact that the right to health is truly universal. It applies without regard to a person's status under immigration law and in all situations, including those attending disaster and forced displacement.

In this paper, we examined obstacles that we observed in fieldwork across six countries that undermine the ability of refugees with disabilities to enjoy adequate health in displacement scenarios. First, drawing on our fieldwork and other recent surveys, we demonstrated that functionality-based questioning—for example by adopting versions of the International Classification of Functioning questionnaires developed by the Washington Group and used by the WHO in its World Report on Disability [12,21]—can help flag disability in displaced populations. The data we, and other researchers, have collected uncover a wide range of functional difficulties, along with information about the causes of these difficulties, which are often connected to the precarious and exclusionary nature of life in displacement. We identified a range of interconnected barriers to health services for refugees generally and those with disabilities specifically. We found that these were often common across the fieldwork settings, despite the very different host country contexts.

However, experiencing health is much more than accessing medical treatment. Our central argument is that the human right to health enshrined in international human rights law requires states (and UN agencies and other humanitarian actors) to consider various determinants of human health, taking into account the lived experience of disability in its many manifestations. We began with the proposition that refugee with disabilities have the same right to adequate health as any person, noting that they face particular challenges in attaining or retaining wellness. Thereafter we showed that the disaggregation of the element of human functioning, alongside an exploration of the individual lived experience, and consultation with people with disabilities, can assist in developing more inclusive strategies. For example, our fieldwork revealed the central importance of access to adequate food and clean water to sustaining bodily functions and maintaining basic hygiene. We observed examples of good practice in countries where measures were adopted to ensure that persons with mobility impairments were given priority in the distribution of food and humanitarian aid or where rations were delivered directly to persons in need. Conversely, we found many instances where persons with disabilities did not have ready access to clean water or to accessible toilets or washing facilities. The inability to maintain personal hygiene is an obvious risk factor for disease and poor general health. Protections against violence and measures to address factors causing or exacerbating disturbed affect are also crucial to the ongoing enjoyment of physical and mental wellbeing. Finally, we found that barriers to health care for refugees with disabilities often resembled the barriers that undermined their participation or access in other areas of their life in displacement, including those that most directly impacted their enjoyment of health, as outlined in Section 5 above.

We accept that war, disaster and displacement pose obvious challenges for all refugees, and especially those with disabilities. Yet, our research suggests that a greater awareness of how disabilities manifest in context and affect an individual's health and wellbeing can lead to improvements in the delivery of humanitarian assistance. The understanding that one size does not fit all—and that accommodations need to be made for different types of impairments—can lead to the adoption of strategies that can make the delivery of assistance more efficient and more effective. As anyone familiar with the principles of universal design will attest, improvements in the accessibility and availability of facilities deliver dividends for everyone, not just refugees with disabilities.

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