UiO **: Faculty of Law**
University of Oslo

# How does MSF work to include persons with disabilities in field missions and projects?

A study on inclusion of persons with disabilities in humanitarian aid

Candidate number: 8001

Supervisor: Peris Jones

Course code: HUMR5200

Number of words: 19365

Submission deadline: August 15th 2020

***Acknowledgments***

I wish to thank my supervisor Peris Jones for his patience and support, as well as constructive feedback and guidance throughout this process. I also want to extend my gratitude towards the MSF movement, and Patrice Vastel especially who, as coordinator for the project on inclusion of people with disabilities, has provided me with valuable guidance and insight. Lastly, I am very much grateful towards my family and my partner for their continued support and interest.

***Abstract***

An estimated one billion people live with some form of disability globally. Yet, persons with disabilities continuously face discrimination, inequality and neglect as a result of barriers based on unawareness, ignorance and exclusion. This thesis explores the importance of specific focus on inclusion of persons with disabilities in situations of risk and humanitarian emergencies, with particular reference to Médecins Sans Frontières' incentive to ensure this. The following discussion explore different approaches to humanitarian organizational change and the philosophy of MSF, as well as the essentiality of inclusion of persons with disabilities in humanitarian with regard to the right to health. In addition, the focus will be on the responsibility of humanitarian actors to provide inclusive work and measures to ensure equal inclusion, with particular focus on the global Covid-19 pandemic. Ultimately, this thesis argues that persons with disabilities require both increased and specified awareness and measures in order to prevent exclusion of people in an already vulnerable state, specifically in line with the CRPD and UDHR, and especially in contexts of humanitarian action. In other words, while medical humanitarian needs remain immense, humanitarian actors must consciously and continuously work to confront and overcome the identified barriers that persons with disabilities face in order to work under humanitarian conditions of equality, impartiality and neutrality.

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| **CESCR** | Committee on Economic, Social and Cultural Rights |
| **CRPD** | Convention on the Rights of Persons with Disabilities |
| **DPO** | Disabled persons' organizations |
| **ESCWA** | Economic and Social Commission for Western Asia |
| **GA** | General Assembly |
| **GNP** | Gross National Product |
| **ICESCR** | International Covenant on Economic, Social and Cultural Rights |
| **IDA** | International Disability Alliance |
| **IHL** | International Humanitarian Law |
| **LGBTQI+** | Lesbian, gay, bisexual, transgendered, queer, intersex+ |
| **MSF** | Médecins Sans Frontières |
| **NGO** | Non-governmental organization |
| **PWD** | Person with disability |
| **WHO** | World Health Organization |
| **RBA** | Rights-based approach |
| **RBD** | Rights-based development |
| **TIC** | Transformational Investment Capacity |
| **UN** | United Nations |
| **TNC** | Transnational corporation |

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# 1        Introduction

Approximately 15 per cent of the world's population, an estimated one billion people, live with some form of disability.[1] Though already a significant group of society, as stated by the Charter on Inclusion of Persons with Disabilities in Humanitarian Action, persons with disabilities (hereinafter referred to as PWDs) 'are disproportionately affected in situations of risk and humanitarian emergencies, and face multiple barriers in accessing protection and humanitarian assistance, including relief in recovery support'.[2] In addition, PWDs are at significant risk of being victims of violence, abuse and/or exploitation – including gender-based and sexual violence.

In a natural catastrophe or in an epidemic outbreak, or during routine vaccination campaigns and general health screenings, this group consistently risk exclusion of their right to health and access to treatment. Indeed, the International Covenant on Economic, Social and Cultural Rights (ICESCR) declare the universal human right to health as 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.[3] Furthermore, in order to establish the evident importance and recognition of the right to health, it is also well-established in the preamble of the World Health Organization's (WHO) preamble – noting that: 'the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition'.[4]

That being said, PWDs are faced with additional barriers (especially in low-income countries) in order to attain the full enjoyment of and access health services and treatment on a general level as well – referring to attitudinal, environmental, and institutional barriers.[5] Attitudinal barriers includes prejudice, discrimination, and stigmatization of PWDs, environmental barriers refers to restrictions linked to access to public transport, hospitals and schools, and public

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[1] World Health Organisation (WHO), 'World Report on disability' (2011) 29

[2] Charter on Inclusion of Persons with Disabilities in Humanitarian Action (2016) para 1.7

[3] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR)

[4] World Health Organization, Constitution (signed 22 July 1946, entry into force 7 April 1948) preamble

[5] Humanitarian Advisory Group, 'Inclusive Humanitarian Action: A study into Humanitarian Partnership Agreement (HPA) Agency practice in the Nepal earthquake response' (2016) 2

information systems.[6] Lastly, institutional barriers concern the exclusion of PWDs in settings of employment or education.

Thus, although the UN Convention on the Rights of Persons with Disabilities (CRPD) commits to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity', the barriers generate health exclusion of a vulnerable minority group. Indeed, especially with regards to low-income countries in which the abovementioned barriers are greater and disability prevalence is higher (18 per cent, compared to 11.8 per cent in high-income countries).[7] Furthermore, humanitarian aid has proven less progressive in its systematic approaches to include PWDs in humanitarian missions according to research.[8] That is, despite the fact that studies find that PWDs constitute a vulnerable group during humanitarian disasters and the subsequent response.[9] For instance, a recent study based on Syrian refugees disclosed that 22 per cent of the participants did indeed have an impairment, including 6 per cent that qualified as to have a severe impairment.[10]

In this context Médecins Sans Frontières (MSF), as an independent and neutral humanitarian actor, encounter PWDs that require access to treatment in line with their global humanitarian response and mission. Yet, research conducted by MSF found that approximately 60 per cent of international staff and 80 per cent of national staff think that they should have or ought to do more with regards to ensure inclusion of PWDs during field missions.[11] This included, amongst other things, ensuring universal access for wheelchair users (both for staff and others), or have to increase focus on PWDs in missions heavily affected by torture.[12]

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[6] Ibid 2.

[7] World Health Organization (n 1) 27

[8] CBM, Humanity & Inclusion, International Disability Alliance, 'Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Update on Progress since the World Humanitarian Summit' (2017) 3

[9] HelpAge International, 'Hidden victims of the Syrian crisis: disabled, injured and order refugees' (2014) 6

[10] Ibid 12: The standard for severe impairment reflect cases where the level of impairment completely or almost completely affect one or more bodily functions

[11] Médecins Sans Frontières, 'MSF national and international field staff survey on inclusion of persons with disabilities' (2017)

[12] Ibid

In total, MSF is made up of 42 000 members and is the largest medical emergency organization in the world.[13] The organization has the majority of their (approximately) 400 projects in low-income countries, and as a result MSF are continuously confronted with situations in which PWDs encounter barriers of institutional-, attitudinal, and environmental character. Thus, the MSF movement voted in favor of the 2016 Motion to Promote Disability Inclusion in MSF, subsequently adopting the motion throughout the organization through the power of MSF's International General Assembly (its highest governing body).[14]

As a result, the "Transformation Investment Capacity" (TIC) project on inclusion of PWDs was established in order to assist the motion implementation in MSF.[15] Nevertheless, despite initiatives as this, the absence of adequate and necessary data on PWDs as well as their access to health services are limited and far from achieving a state of progression and satisfaction. For instance, there is a pressing need for – though a continuous shortcoming in – a sign of products, programs, and services as referenced in the Convention on the Rights of Persons with Disabilities.[16] Therefore, this thesis project aims to contribute to an increased level of academic research and awareness of PWDs in humanitarian missions.

This thesis will research MSF's engagement with ensuring the inclusion of PWDs in field missions and projects in accordance with their adopted motion. Specifically, it aims to provide a sufficient base upon which to build understanding of MSF's efforts to ensure access to health services for PWDs. Thus, the project will research MSF's process of inclusion of PWDs, and further analyze both previous and current challenges in field projects. Moreover, it will aim to identify key methods of inclusion that corresponds with a universal design with regards to PWDs as referred above. In order to illustrate the challenges and findings, a case study on the 2019/2020 Covid-19 pandemic is provided.

### 1.1.1 Research questions

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[13] Médecins Sans Frontières, *Who we are: We are Médecins Sans Frontiéres* (n.d.)

[14] See Patrice Vastel, *Motion 1: Promote Disability Inclusion in MSF* (2016)

[15] Patrice Vastel, *Taking forward the motion on People with Disabilities* (2018)

[16] UN General Assembly, Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res/61/106 2515 (CRPD) Art. 2

In order to explore how MSF work to include PWDs in field projects and missions, the research presented in this thesis is all based on three main questions – reflected through the three main chapters. Each of these will include one to two sub-questions in order to specify the research and thus provide structure to the thesis project. The research questions are as follows (provided with their sub-questions respectively):

- Why is inclusion of persons with disabilities essential in humanitarian action in particular?
    - 1st sub-question: why is it relevant to focus on inclusion of persons with disabilities?
    - 2nd sub-question: how does the inclusion of persons with disabilities in humanitarian action relate to the human right to health?
- How can persons with disabilities sufficiently be included in MSF projects?
    - 3rd sub-question: who are the patients that do not access MSF services?
    - 4th sub-question: what are the barriers which hinder persons with disabilities to access MSF services?
- How does MSF work to include persons with disabilities in field missions and projects?
    - 5th sub-question: to what extent has MSF established inclusive structures?

## 1.1.2 Research approach

This thesis project will research the process of how MSF works in order to include PWDs in their projects. Ultimately, that entails elaborating on importance of PWD inclusion and how it ought to be an essential and active focus in humanitarian action in order to ensure equal access to health services. Thus, the research requires an analytical approach towards both previous and current challenges in MSF projects. Furthermore, data collection is based on empirical references – both in forms of academic journals and articles, as well as interviews and internal MSF documents. The interdisciplinary approach combined with the qualitative approach will first establish a discussion on different approaches to transformative measures among development and humanitarian actors. Then, a legal basis of the right to health is presented through international conventions and legal treaties, before establishing the importance of PWD inclusion specifically in relation to MSF.

The thesis will also explore the MSF's effort to actively reach out to disabled people's organizations (DPO's). These organizations create a basis for theorical framework through their research and surveys, essentially helping to establish an understanding of PWDs' challenges locally. Additionally, some of the main organizations contributing to this thesis are: HelpAge International (through its "Age and Disability Capacity Programme"); International Disability Alliance (through its "Humanity and Inclusion" inititive); and World Health Organization (WHO).

## 1.2     Methodology

Previous research argues that raising awareness of PWDs and identifying barriers is key in order to progressively create inclusion – which is the overall common consensus. As a result, research conducted in order to establish an academic basis in this particular context, has relied on peer-reviewed journals. Furthermore, this thesis is multidisciplinary – i.e. it includes components from different legal and political science approaches and perspectives. In this regard, international conventions and treaties will create the legal basis. Consequently, the research will be based upon a qualitative methodology, where primary sources ensure a specific relevance to MSF.

The primary methods of research were a qualitative study, and subsequent data collection are based on Alan Bryman's book on social research methods. As part of the qualitative study, an interview was conducted with the appropriate considerations of professionalism and protection of the source. Further research methods, limitations and ethics is elaborated below.

The primary sources are through connections made in the MSF movement. Former General Director of MSF Norway, Patrice Vastel, is the current coordinator for promoting PWD inclusion in MSF internationally, and subsequently represents a focal point in the primary research presented. Permission was given to use his full name and title for this research project. He additionally represents a part of the PWD community as he himself has a hearing disability, although he does not obtain the experience as a patient. Moreover, in accordance with the newsletters provided through his project, further information provided by primary sources (primarily MSF fieldworkers) is referenced and analyzed.

Due to Covid-19, the interview with Vastel was conducted through an online meeting the 29th of April 2020, as well as small follow-up sessions after. Prior to the interview, he was provided a research participant consent form which was signed in advance of the session in order to ensure that the appropriate ethics of research is maintained. Research ethics is further elaborated in section 1.2.3.

The literature review will set the theoretical framework through textual analysis, as well as to examine theories through different standpoints, both in general and in an MSF context. This corresponds with the comparative legal methods of law-in-context. That is, essentially to argue that law is a social phenomenon both due to strong role in society, and as a result of how the quality of law is heavily reliant on societal factors and belief.[17] Furthermore, the literature review will also include official reports from NGOs, academic journals, and UN documents (both legal and non-legal).

Through the abovementioned referred methodology, both barriers and corresponding key methods of inclusion will be analyzed in order to establish a universal design of products, programs, and services to ensure PWD inclusion in MSF field missions and projects.

## 1.2.1     Case study

In order to put the theory into practice, a case study is presented that will explore to which extent MSF has established inclusive structures in the field. The case study will be based on MSF's measures to ensure inclusion of PWDs in its Covid-19 response during the first six-seven month of 2020. Moreover, the case study contributes to illustrate the importance of case approaches for evaluating organizational human resources (HR)- and policy measures in MSF. More specifically, this will entail analyzing the organizational structure alongside the concluding practical measures in field projects – e.g. always providing both visual and audio information.

## 1.2.2     Research limitations

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[17] Carlo Focarelli, *International law as a social construct: the struggle for global justice* (1st edn. Oxford University Press 2012) 33

Firstly, although Foucault did argue that 'one ought to read everything, study everything', the simple essence of this is unachievable.[18] As a result, a potential limitation to this study can be the failure of including all relevant research and texts. Paradoxically enough, part of this thesis focus on the inadequacy and limited research and data on PWD inclusion in humanitarian missions. Thus, the probability of engaging with recent and relevant research is considered high. Indeed, several humanitarian actors as well as academics have engaged in efforts and created reports and recommendations on this, however not specific to this context. As a result, the research aims to have a well-rounded representation of humanitarian organizations' commitment to ensure inclusion of PWDs. In particular, MSF's organizational efforts of inclusion, as well as the fieldworker's practice, and the patients' experience.

The data collection is based on both primary, secondary, and tertiary sources – essentially establishing a representative foundation for post-modern standpoint theory.[19] This theory aims to create an increased understanding and point of view of the case in study (e.g. PWDs). Thus, creating an objective outlook in order to fully comprehend the standpoint of the excluded and oppressed. Nevertheless, difficulties related to the process of monitoring and assessing the inclusion of PWDs in humanitarian action might occur as a consequence of the narrow scope of research already conducted and available. Particularly in relation to MSF. Furthermore, limitations can occur – especially with regards to the recorded experience of patients. Due to patient's health and sensitivity, much of the information and references corroborating patients with disabilities is based upon secondary references based on the experience of humanitarian actor(s).

Second, the access for relevant interview subjects proved to a be a challenge. Both due to patient sensitivity and the subsequent confidentiality of MSF, as well as the broad stigmatization of PWDs in many cultures. In this regard, the main interview subject, Patrice Vastel, has had an absolute essential role. Therefore, ethical research considerations are of essence as elaborated in 1.2.2. Furthermore, as MSF provide free health services, the possibility for blurred lines and a conflict of interest in an interview setting is not unthinkable for a former patient turned primary source.

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[18] Michel Foucault, *Aesthetics, Method, and Epistemology* (The New York Press 1998) 263

[19] Sandra Harding, 'After Mr. Nowhere: What Kind of Proper Self for a Scientist?' [2015] 1(1) Feminist Philosophy Quarterly 2

Lastly, this thesis was impacted by the worldwide pandemic of Covid-19 in 2020 – mostly related to deadlines and the process of interviews.

### 1.2.3    Research ethics

When engaging with primary sources and conducting interviews, it is of absolute essence to maintain ethical research, and subsequently preserve professionalism and protection for the source. George Ulrich argues that it is in fact possible to restrict the number of basic normative considerations and commitments.[20] He thus identifies five categories in total to address ethical considerations in human rights research:

> (i) *no-harm issues*, i.e. the direct, indirect, physical, material, or psychological (immediate or long-term) affect of one's actions and decisions upon others;

> (ii) *recognition and respect,* i.e. acknowledging and recognizing the autonomy of research participants, and ensure correlation of research expectations;

> (iii) *beneficence and justice*, i.e. issues regarding promoting the greater good, and preventing wrongdoing, and ensure fair distribution of goods;

> (iv) *collaboration and possible conflicts of interest,* issues regarding correct conduct, and ensure the absence of deception;

> (v) *scientific and professional standards,* issues regarding compliance and institutional policies.

For instance, in order to ensure correlation of research expectations, the researcher provides the interview subject(s) with a copy of the thesis. That is (often in addition to the participants personal interest), to guarantee an accurate reflection of the interview and its outcome. Furthermore, the interview participant was provided with an approved and informed consent form which was signed in advance of the interview in order to clarify and ensure the abovementioned research ethics.

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[20] George Ulrich, 'Research ethics for human rights researchers' in Bård A. Anderassen and others (eds.) *Research Methods in Human Rights. A handbook*' (Edward Elgar Publishing 2017) 194, 195

In addition, conducting ethical research also entail thorough evaluation of the following principles: '(i) whether there is harm to the participants; (ii) whether there is a lack of informed consent; (iii) whether there is an invasion of privacy; (iv) whether deception was involved'.[21] Therefore, in order to ensure the four abovementioned principles, the interviews conducted aimed to be open-ended in order to avoid deception or influence by the researcher. In addition, the interview subjects were provided an approved and informed form of consent to ensure consent and simultaneously avoid harm.

## 1.3    Key concepts

*Accessibility*

A cornerstone of inclusive humanitarian aid. Concerns how an environment, service, or product can be accessed by as many people as possible. [22] Progressive access includes identifying and improving barriers to ensure accessibility.

*Barriers*

The overall present or absent factors in person's environment that limit functioning and create disability. These include, but are not limited to, attitudinal, environmental, and institutional barriers.[23]

*Humanitarian aid*

Humanitarian action and aid is a reaction to humanitarian needs, e.g. food, clean water, and basic health. Therefore, it can take various forms, including 'provision of money, food, seed, clean water, irrigation, training of medical professionals, medical services and equipment'.[24]

*Inclusion*

The Humanitarian Advisory Groups defines 'inclusion' accordingly: 'actions taken to ensure the right to information, protection and assistance for all persons affected by crisis, irrespective

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[21] Alan Bryman, *Social Research Methods* (3rd edn. Oxford University Press Inc 2008) 118

[22] Supriya Akerkar and Rhea Bhardwaj, 'Good practice guide: embedding inclusion of older people and people with disabilities in humanitarian policy and practice' (2018)

[23] Centers for Disease Control and Prevention, *Disability Barriers to Inclusion* (2018)

[24] Jennifer Szende, 'Humanitarian Aid' in Deen K. Chatterjee (eds.) *Encyclopedia of Global Justice* (Springer 2011) 509

of age, sexual and gender identity, disability status, nationality, or ethnic, religious or social origin or identity'.[25] In addition, the act of inclusion also mean 'identifying and removing barriers so that those individuals and groups who are vulnerable, marginalized and/or excluded can participate in decision-making and benefit from humanitarian action on an equal basis with others'.[26]

*Médecins Sans Frontiéres (MSF)*

A non-profit and member-based non-governmental organization (NGO) working to provide medical assistance to persons impacted by epidemics, conflict, disasters, or health care exclusion. It is directed by medical ethics as well as based upon the principles of impartiality, neutrality and independence.[27]

*Persons with disabilities*

This thesis basis its understanding of "persons with disabilities" on the United Nations Convention on the Rights of Persons with Disabilities' (CRPD) definition of persons with disabilities, i.e. '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'.[28]

## 2      Literature review

In order to contextualize and provide a theoretical framework for the inclusion of PWDs in MSF field projects, this literature review will address central core literature related, ongoing debates on humanitarianism, organizational change in MSF, as well as to establish a discussion on a rights-based approach (RBA). That is, in order to analyze and compare the current MSF build-up and structure of PWD inclusion in relation to the more conventional RBA. Thus, relatable literature includes NGO reports on disability inclusion in relation to conflict, disaster

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[25] Humanitarian Advisory Group, 'Inclusive Humanitarian Action: A study into Humanitarian Partnership Agreement (HPA) Agency practice in the Nepal earthquake response' (2016) 4

[26] Australian Red Cross, 'Disability Inclusion and Disaster Management' (2015) 3

[27] Médecins Sans Frontières, (n 13)

[28] UN General Assembly, Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res/61/106 2515 (CRPD) 4

management and emergencies, as well as debates on the human rights responsibilities of non-state actors.

The obligation of States to protect and ensure the PWDs is outlined in the UN Convention on the Rights of Persons with Disabilities (CRPD). This especially is in reference to PWDs in situations of risk – including armed conflict.[29] Still, disabilities have been thought to be neglected and receive less attention in humanitarian action despite solid documentation proving that PWDs are increasingly vulnerable in situations in need of humanitarian aid.[30] Indeed, the Office of the United Nations Disaster Relief Coordinator argued in 1982 that 'it is not sufficiently widely realized how greatly the disabled members of a community are dependent upon others because of their physical and/or mental impairments or disabilities, nor that they are unable to respond to emergency warning as others do'.[31]

Disability is a broad term that refer to a spectrum of impairments. The UN Convention on the Rights of Persons with Disabilities (CRPD) define PWDs as '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'.[32] Nevertheless, even though it is not a disability per definition, health exclusion also frames those who are members of the LGBTQI+ community, or minority political or religious affiliations.[33] Moreover, it additionally affects those that have a short-term disability as well – e.g. pregnancy, or temporary illness or injury. Pregnancy and reproductive health are also one of the key factors exposing women to a heightened risk of acquiring a disability – that includes long-term and permanent impairment as well.[34]

Although there have been some recent definite and vital research and measures taken in order to ensure awareness and inclusion of PWDs in humanitarian action, there are still big gaps. Valuable research includes key messages that point out the importance of strengthening

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[29] Maria Kett and Mark van Ommeren, 'Disability, conflict, and emergencies' [2009] 374(9704) The Lancet 1801

[30] Arnold R. Parr, 'Disasters and disabled persons: An examination of the safety needs of a neglected minority' [1987] 11(2)

[31] UNDRO, *Disasters and the Disabled* (1982) Office of the United Nations Disaster Relief Coordinator Ch. 4

[32] UN General Assembly (n 16) 4

[33] LGBTQI+ referring to the lesbian, gay, bisexual, transgendered, queer, and intersexual community.

[34] Stine Hellum Braathen, Poul Rohleder, Gloria Azalde, 'Sexual and reproductive health and rights of girls with disabilities' (2017) SINTEF

assessment tools, developing guidance and tools accustomed for the disability context, strengthening national shelter systems, and promote investments in disability inclusion projects.[35] Yet, disability inclusion suffers negligence and exclusion as a result of lacking universal measures for NGOs.

In order to illustrate how PWDs are often overlooked, an example is from the recent Economic and Social Commission for Western Asia (ESCWA) report on 'Disability in the Arab Region'. According to the report, only 2 per cent of the Arab population is reported to have a disability – in severe contrast to the global average of 15 per cent.[36] Moreover, it reported an internal variation in the region of people living with a disability from 0.2 per cent in Qatar to 5.1 per cent in Morocco. As a result, it becomes even more clear that disability remain one of the most overlooked matters, despite being one of the most significant causes of disadvantage and marginalization.

Luckily, MSF have put efforts to make organizational change in order to ensure inclusion and this thesis aim to provide a sufficient base to comprehend MSF's efforts to ensure just that: access to health services for PWDs. It will argue that by adopting a rights-based approach, MSF could increase organizational transparency and accountability. Nevertheless, on the account of efficiency, a right-based approach could subsequently create more bureaucracy due to necessary reporting and stricter implementation.

## 2.1    Exploring a rights-based approach (RBA)

First, even though there is some debate on whether to draw a distinction between the terms 'rights-based approaches' and 'human rights-based approaches', or if they are indeed one and the same thing, this thesis (like many) adopts the latter assumption. That is, although some consider "human" to imply an 'eminence of the legal implications and normative quality of human rights as defined within international law', others simply regard 'rights-based approach' as an umbrella for both terms.[37]

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[35] Global Shelter Cluster, 'Disability Inclusion in Shelter and Settlements Programming' (2019)

[36] Economic and Social Commission for Western Asia, 'Disability in the Arab Region' (2018) 14

[37] Hannah Miller, 'From rights-based' to 'rights-framed' approaches: a social constructionist view of human rights practice' [2010] 14(6) The International Journal of Human Rights 917

Rights-based approaches (RBA) were first developed through the development sector and later emerged in other areas. For scholars and development actors, RBA is currently the predominant approach of human rights practice and discourse.[38] As it commenced, the main focus concerned the shift from targeting vital 'needs' to then claiming and protecting 'rights'.[39] In practice, the approach is dependent upon active participation involving advocacy in order to aid the poor and excluded.[40] Moreover, RBA requires analysis and programming based on rights standards and principles as well as acknowledging the evidential duty-bearer role of the State.[41]

In this regard, and as will be referenced in later chapters, the duty-bearer role of the State includes both negative and positive obligations in reference to international human rights law. The positive obligations of States are in correlation with Asbjørn Eide's tripartite typology to analyse the nature of economic and social human rights. Essentially, this entailed three layers of State obligations: to respect-, to protect-, and to fulfil human rights.[42] The obligation to protect recognises the assumption that third parties can potentially interfere with the freedoms of right holders to fulfil their own rights. Thus, States obtain a positive duty to ensure protection against such interreference – meaning States have to take necessary measures in order to protect a right. Or rather, ensure protection by adopting reasonable and appropriate measures in order to safeguard the right of individuals.[43]

Although it is hard to pinpoint the exact moment of its emergence, several development actors began to adopt and promote RBAs from the mid-1990s onwards – including UN agencies, non-governmental organizations (NGOs) and social movements.[44] Together UN agencies have agreed that a RBA have a number of essential characteristics:

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[38] Hannah Miller and Robin Redhead, 'Beyond 'rights-based approaches'? Employing a process and outcomes framework' [2019] 23(5) The International Journal of Human Rights 700

[39] Maxine Molyneux and Sian Lazar, *Doing the rights thing: rights-based development and Latin American NGOs* (ITDG Publishing, 2003) 6

[40] Paul J. Nelson and Ellen Dorsey, 'Who practices rights-based development? A progress report on work at the nexus of human rights and development' [2018] 104 World Development 99

[41] Brigitte I. Hamm 'A Human Rights Approach to Development' [2001] 23(4) Human Rights Quarterly 1014

[42] Asbjørn Eide, *The Right to Adequate Food and to be Free from Hunger. Updated Study on the Right to Food,* UN Doc E/CN.4/Sub.2/1999/12 (28 June 1999) [4]

[43] United Nations Office on Drugs and Crime (UNODC), *Positive and negative obligations of the State* (n.d.)

[44] Including: UNDP, UNCEF, UNHCHR, Oxfam International, Save the Children, and CARE International. See Hannah Miller and Robin Redhead, 'Beyond 'rights-based approaches'? Employing a process and outcomes framework' [2019] 23(5) The International Journal of Human Rights 702

- the main objective of development policies and programs should be to fulfil human rights;
- a RBA identifies and focus on strengthening rights-holders and their entitlements, and corresponding duty-bearers and their obligations;
- the guideline for all development and programs should be based on international human rights treaties.[45]

The approach is foremost concerned with the relationship between a state and its citizens. As abovementioned, RBA identifies both duty-bearers (the State) and right-holders (the citizen) in order to establish a balance of human rights legal obligations and accountability.[46] By addressing inclusion of PWDs by a RBA through States and UN agencies has resulted in the establishment of the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Moreover, and perhaps more importantly, the Convention on the Rights of Persons with Disabilities (CRPD) is another essential outcome of a RBA to inclusion and legal accountability in reference to PWDs.

Based on the above definition, a rights-based approach to PWD inclusion ought to be a given. It should subsequently be the preferred and most effective method of implementation for MSF. However, sociologist Hannah Miller argues that as the hegemony of RBA increases, so does the inability to conduct humanitarian agendas in an effective and sustainable manner simultaneously.[47] Meaning, when humanitarian actors adopt a RBA, the organization risk being less sufficient in their social mission – much due to more bureaucracy and reporting, and less hand-on work in the field. Thus favoring an approach outside of RBA when arguing that 'much more can be done with human rights', especially in consideration of the level of human rights integration and development outside the borders of RBA.[48] It could also include the ways in which activities are assessed in line with human rights norms, however not directly through a RBA.[49]

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[45] Jakob Kirkemann Boesen and Hans-Otto Sano, 'The implications and value added of a human rights-based approach' in Bård A. Andreassen and Stephen P. Marks (eds.), *Development as a Human Right. Legal, Political and Economic Dimensions* (2nd edn, Intersentia 2010) 50, 51

[46] Ibid 50.

[47] Miller (n. 38) 700

[48] Peter Uvin, 'From the right to development to the rights-based approach: how 'human rights' entered development' [2007] 17(4-5) Development in Practice 604

[49] See Laure-Hélène Piron with Tammie O'Neil, 'Integrating Human Rights into Development: A synthesis of donor approaches and experiences' (2005) Overseas Development Institute

Or perhaps RBA could, as a result of explicit incorporation of human rights strategies, set boundaries for the organizational change and development.[50] Nevertheless, adopting the structure of a RBA is arguably not the better fit for MSF and similar organizations. Both on the account of the necessary levels of accountability resulting in increased resources devoted to reporting and implementation, in addition to a more demanding standard of transparency. This will be addressed later in this chapter.

### 2.1.1 How do INGOs adopt RBA?

In general, there is broad compliance that an RBA acknowledges people as key actors in their own development, and that the duty-bearer is responsible for enabling the rights-holders to recognize and exercise their rights.[51] Moreover, the RBA have been adopted as a strategy prone to address inequalities through measures of empowering marginalized groups as well as strengthening the level of accountability.[52] Hence it has also been greeted with optimism based on the opportunity humanitarian actors now obtain to embrace a strengthened approach to interventions.[53]

A different method to approach humanitarian aid projects, it through a needs-based approach. The needs-based approach aims to add increased objectivity to the process of determining who receives aid and how, primarily by using documentation and testimonies to reflect the need.[54] Thus, the approach introduce an effective and efficient method of intervention. Nevertheless, the needs-based approach also has a tendency to be based on the values of the political elite – which not necessarily reflects the values nor the perspectives of those in need of aid. This is because the needs-based approach essentially values the achievement of established goals,

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[50] See Wouter Vandenhole and Paul Gready, 'Failures and Successes of Human Rights-Based Approaches to Development: Towards a Change Perspective' [2014] 32(4) Nordic Journal of Human Rights

[51] Andrea Cornwall and Celestine Nyamu-Musembi, 'Putting the 'rights-based approach' to development into perspective' [2004] 25(8) Third World Quarterly

[52] Raymond C. Offenheiser and Susan H. Holcome, 'Challenges and Opportunities in Implementing a Rights-Based Approach to Development: An Oxfam America Perspective' [2003] 32(2) Nonprofit and Voluntary Sector Quarterly

[53] See Jim Ife, 'Needs, Rights and Democratic Renewal' [2009] 22(1) Nouvelles pratiques sociales 49

[54] S. Megan Berthold, *Human Rights-Based Approaches to Clinical Social Work* (1st edn, Springer International Publishing, 2015) xi

instead of the process of developing the goals. Thus, potential negative outcomes are often associated with the personal attributes and/or behaviors of the group or individual receiving aid.[55]

For instance, in a needs-based approach, a person diagnosed with a mental disorder will often receive services based on the authorities or expert's own determination of what is best for the person. As a result, it is often assumed that the mentally disordered person in unable to make "good" choices. Thus, success (in this scenario) is measured according to adherence to the pre-scribed treatment plan – a plan that is essentially prescribed by an authority that could disregard subject needs, objections, or personal assessments.[56]

Thus, by adopting an RBA, the human services and humanitarian organizations have responded to this issue. In moving from a needs-based approach, humanitarian actors enable an enhanced practice of organizational democracy and practices of progressive politics through adopting a RBA.[57] The aspect of using rights as a more active component in order to emphasize the per-spective of the person(s) concerned, and consequently removes the "deficit" that is apparent and inherent in a needs-based approach.[58] That makes a RBA arguably a more effective method compared to deficit-based approaches which essentially emphasize people's deficiencies – that is, creating a forum of alliance and accountability between the humanitarian actor and the per-son in need of aid.[59]

Another approach to humanitarian work is through rights-based development. A rights-based development (RBD) approach is a comprehensive process that advance beyond social, cultural, and political spheres in order to aim for "constant improvement" – i.e. continuous and dynamic improvement of well-being.[60] The perhaps most essential aspect of RBD is the application of the concept of rights – similarly to a strict rights-based approach.[61] Indeed, RBD focus on the

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[55] Ibid xi.

[56] Ibid xi.

[57] Ife (n 53) 42

[58] Ife (n 53) 42

[59] See Dennis Saleebey, 'Power in the People: Strengths and Hope' [2000] 1(2) Advances in Social Work

[60] Arjun Sengupta, 'The Human Right to Development' in Bård A. Andreassen and Stephen P. Marks (eds.) *Development as a Human Right. Legal, Political and Economic Dimensions* (2nd edn, Intersentia 2010) 16

[61] Morten Broberg and Hans-Otto Sano, 'Strengths and weaknesses in a human rights-based approach to international development – an analysis of a rights-based approach to development assistance based on practical experiences' [2017] 22(5) The International Journal of Human Rights 667

efforts to actually fulfil rights, and not only as efforts of charity. As a result, development through a rights-based approach contribute to a human rights realization for the right-holders – in addition to advocating for claiming their rights.

Though not rigorously the same, the right to development encompasses the approach of rights-based development. The right to development is defined by the Declaration on the Right to Development through the Preamble and Article 1: 'The Right to Development, which is an inalienable human right, is the right to a particular process of development in which all human rights and fundamental freedoms can be fully and progressively realized'.[62] RBD is distinct from the more traditional definitions of development through measures of Gross National Product (GNP), industrialization, exports-growth, or capital inflows.[63] Meaning that the process of RBD require genuine participation, alongside a fair and equitable distribution of benefits that consequently result in the progressive improvement of everyone – not only certain economic groups.[64]

That is not to say that a process of RBD and the right to development is necessarily the same thing. Meaning, that any process of development, can indeed be rights-based – given that the process implements and is consistent with human rights standards. Thus, when that process of development is able to be a right and subsequently claimed as a right, it can be set in the name of the right to development.[65] In sum, the rights-based process of development can be object of the right to development by conforming the human rights standards in consistence with the definition of development in the Declaration on the Right to Development.

### 2.1.2 RBA and RBD in the humanitarian sector

Traditionally in political theory, human rights are both moral and legal entitlements for individual protection from political and societal threats.[66] This includes protection from threats to

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[62] See Sengupta (n 60) 15; Declaration on the Right to Development (4 December 1986) UNGA A/RES/41/128 Preamble and Art. 1

[63] Sengupta (n 60) 16

[64] Sengupta (n 60) 16

[65] Sengupta (n 60) 16

[66] Bård A. Andreassen, 'Development and the human rights responsibilities of non-state actors' in Bård A. Andreassen and Stephen P. Marks (eds.), *Development as a Human Right. Legal, Political and Economic Dimensions* (2nd edn, Intersentia 2010) 149

the rights related to freedom, a decent living, as well as functions of political, economic and social behavior. During the period of modern history, instances of authoritarian and totalitarian state power, and the subsequent abuses of state governance, have generated a risk of such threats. Consequently, the original human rights vision became to regulate and humanize state power – thus creating a global sphere of decent governance standards for state behavior alongside respect of basic human rights.[67]

Yet, how do non-governmental organizations (NGOs) fit in the framework of human rights responsibilities? Generally, the state has obtained the privilege of defining state-citizen relationship. Furthermore, the state will continue to be the absolute key force of human rights for now. Nevertheless, the UN Independent Expert on the Right to Development argued that the 'obligation to facilitate the rights-holders' realizing of their claims falls not only on States nationally and internationally, but on international institutions, on the civil society, and on anybody in the civil society in a position to help. NGOs are one constituent of civil society that can and has often played a very effective role in the implementation of human rights.[68]

Although many theoretical matters with regards to international human rights law require a state-centric structure, one can conclude that the application of human rights law in order to establish human rights responsibilities for non-state actors and organizations is advancing.[69] Particularly with regards to Transnational corporations (TNCs), however also when considering NGOs, as both sectors are influenced by human rights soft law and voluntarism simultaneously.[70] Moreover, non-state actors are additionally affected by national case law with reference to international human rights law for definitions as well as specifications of human rights responsibilities.[71]

Therefore, when considering the human rights responsibilities of NGOs alongside the prevailing stigmatization of PWDs and the constant impact of barriers encountered, it is evident that PWDs are included and emphasized in humanitarian action. Not only in accordance with the

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[67] Ibid 149

[68] UN Economic and Social Council, "Third Report of the Independent Expert on the Right to Development", UN Doc. E/CN.4/2001/WG. 18/2, para. 25

[69] Andreassen (n 66) 173

[70] Andreassen (n 66) 173

[71] Andreassen (n 66) 173

moral and legal human rights protections, however also with regards to ensuring ethics and mandates established by NGOs.

However, with regards to medical emergency management, neither awareness nor inclusion of PWDs is adequate – that is, in spite of both the high number of PWDs identified and their subsequent condition.[72] Furthermore, the majority of research conducted on the subject addresses the emergency structures and disaster management from a State-oriented point of view. In this regard, Kyoo-Man Ha found that different nations and various cultures do indeed have contrasting models of conduct when addressing PWDs. For instance, Ha indicated that moral inclusion was favored in Indonesia – primarily as a result of the compassion and empathy other residents have for PWDs. Meanwhile Korea focused extensively on inclusive medical treatment, and the US aim attention towards social inclusion. Still, Ha also concluded that PWDs have not successfully been entirely included – regardless of nationality.

As a result, it is crucial that the humanitarian sector direct attention towards PWDs awareness, and thus identify barriers in order to concur them in emergency responses. Consequently, the Humanitarian Advisory Group together with CARE, Oxfam, Caritas Nepal, Plan Australia and others set forth a report addressing PWDs in the aftermath of the earthquake in Nepal in 2015.[73] This report concluded that despite the strong commitment towards inclusion among the humanitarian sector, more action ought to be taken in order to systematically reach and ensure access to treatment of PWDs. In addition, the report found that the necessity of having a universal structure and design is essential, hence the recommendation that this would be achievable through trainings, preparedness, response and recovery programming, as well as continued research.

Nevertheless, despite increased awareness of PWDs and the subsequent enhanced adoption of a rights-based approach to inclusion in the humanitarian sector, PWDs are still subject to discrimination and exclusion. In 2015 the Global Shelter Cluster (GSC) published a report in collaboration with CBM, Handicap International and IFRC, essentially arguing in favor of a

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[72] Kyoo-Man Ha, 'Inclusion of people with disabilities, their needs and participation, into disaster management: a comparative perspective' [2015] 15(1) Environmental Hazards

[73] Humanitarian Advisory Group (n 5)

transformation in humanitarian organization's approach to both inclusion and accessibility.[74] The report defines 'inclusion' as a 'rights-based approach to community programming, aiming to ensure persons with disabilities have equal access to basic services and a voice in the development and implementation of those services'.[75]

Ultimately, a RBA would be inadequate if it failed to achieve a positive transformation for development and humanitarian actors.[76] Thus, by adopting a RBA, MSF can examine their strategy and how it affects the lives of their patients and their subsequent claim for accountability.[77] Moreover, it could strengthen the level of critical self-awareness in MSF, in addition to contributing to increased focus on inherent inequalities in MSF missions. Therefore, a RBA would arguably be the preferred approach to address PWD inclusion in the humanitarian sector – and MSF in particular.

Adopting a RBA has also proven to be a challenge for parts of the humanitarian sector nonetheless. Specifically, disability-specific NGOs and disabled people's organizations (DPOs) have long seen themselves as responsible for advocacy and supporting PWDs in claiming their rights.[78] When the CRPD ratified these rights, several of these organizations found themselves expanding their role to broader reach as 'facilitators of disability mainstreaming in development'.[79] Thus, somewhat changing the organizations' identity and strategic direction: that is, from a position as implementer or activist to instead an organizer of change; moreover, repositioning their focus on PWDs to an increased focus on social actors that implement the CRPD. Consequently, to how such change requires allocating resources and funding, both NGOs and DPO were hesitant to implement a influenced RBA. Not only is it necessary to allocate

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[74] International Federation of Red Cross and Red Crescent Societies, 'All Under One Roof: Disability-inclusive shelter and settlements in emergencies' (2015)

[75] Ibid 10.

[76] Andrea Cornwall and Celestine Nyamu-Musembi, 'Putting the 'rights-based approach' to development into perspective' [2004] 25(8) Third World Quarterly 1432

[77] Ibid 1432

[78] Joske G. F. Bunders, Saskia C. van Veen, and Barbara J. Regeer, 'Meeting the Challenge of the Rights-based Approach to Disbility: The Changing Role of Disability-Specific NGOs and DPOs' [2013] 31(3) Nordic Journal of Human Rights 39

[79] Ibid 39.

resources internally when adopting a RBA, studies also found that NGOs must progress their selective measures when determining who to receive funding from as well.[80]

Nevertheless, the actions of MSF are first and foremost medical. Although the RBA discussion have been prevalent internally, MSF is, at the end of the day, not a human rights organization – meaning that is does not actively promote human rights as such. The organization provides medical aid based on the principles of medical ethics (elaborated in the below section), which is essentially the core of MSF. In brief, MSF does not defend human rights per se, but it defends inherent humanity and ethics – which in many ways is reflected in human rights treaties. Thus, RBA is arguably not the better fit for the MSF structure.

Metaphorically put, an example of MSF's philosophy of how human rights ought to be and is a "given" to all humanity is through a legal case in Italy in 2016. As food theft in Italy is not ruled a crime if one is poor and hungry because 'ad impossibilia nemo tentur' – no one is expected to do the impossible; that is, survive without food or water.[81] In a similar matter, MSF expects human rights and its standards to be upheld – just as the basic standard of life is reflected in this instance by not punishing the theft. MSF does not adopt a RBA because it considers human rights to be universal to humans – regardless of race, religion, ethnicity, nationality, or disability. Thus, MSF adopts a natural school of thought with regards to human rights, i.e. human rights are considered as universal simply because it is an inherent moral of human nature.[82] As a result, humans have human rights simply because we are human beings. Through this perspective, MSF does not need a RBA because 'the source of human rights is man's moral nature' – i.e. a given – and is therefore based on medical ethics as approach.[83]

In addition to based on a medical ethics approach, MSF also adopts a patient-based approach through its work. Therefore, aligning their primary mandate – i.e. to bring emergency medical assistance to populations in need. A patient-based approach focuses on the respect, empowerment, involvement, access, support of the patient in order to better meet the needs of the

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[80] Babatunde Olawoore, 'The implications of the rights-based approach on NGOs' funding' [2017] 27(4) Development in Practice 526

[81] Gaia Pianigiani and Sewell Chan, 'Can the Homeless and Hungry Steal Food?' *The New York Times* (May 3, 2016)

[82] Marie-Bénédicte Dembour, 'What Are Human Rights? Four Schools of Thought' [2010] 32(1) Human Rights Quarterly 7

[83] Jack Donnelly, *Universal Human Rights in Theory & Practice* (2nd edn. Cornell University Press 2003) 14

patients.[84] It therefore differs from a RBA and RBD; namely due to its primary patient-centered focus, in contrast to a "outward" focus on rights that aim to benefit the patient. Thus, essentially creating an approach of need-based and patient-centered medical humanitarianism.[85]

## 2.2     What are 'medical ethics'?

MSF was first created by French doctors and journalists in 1971, namely as a result of ideological disagreement with the established practice of political silence during the Biafran War in the Red Cross Movement.[86] MSF is subsequently based on the ideas of medical action and *témoignage* – i.e. the principle of "bearing witness" through vocalizing occurrences and circumstances from the field. Moreover, the organization is made up of 24 associations which ensures a democratic was of governance. Even though the scope of activities for the organization is predominantly based on emergency relief, MSF has taken on a broader range of schemes by extending the term 'crisis' to include neglected diseases, underserved populations, acute disasters, and conflicts.[87] In  1999, MSF was awarded the Nobel Peace Prize 'in recognition of the organization's pioneering humanitarian work on several continents'.[88] The prize money helped to create MSF's Access Campaign – a campaign with aim to increase advocacy and engagement related to global health policies and access to health.

As abovementioned, the actions of MSF are first and foremost medical. It is therefore evident to have a good comprehension of the definition of 'medical ethics'. *Ethics* derives for the Greek *ethos,* meaning 'custom or practice, a characteristic manner of action, a more or less constant mode of behavior in the deliberate actions of men'.[89] Essentially, ethics helps us to judge both the morality of the good and bad of our actions. Under medical circumstances, ethics often involve life and death.[90] Which is natural – as medical ethics involves the obligations of doctors

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[84] International Alliance of Patients' Organizations: a global voice for patients, 'Patient-Centered Healthcare Indicators Review' (2012) 5

[85] Médecins Sans Frontières Analysis: Reflection on Humanitarian Action, 'Medical Humanitarian Needs in a Changing Political and Aid Environment' (26 June 2019)

[86] Philippe Calain, 'In Search of the 'New Informal Legitimacy' of Médecins Sans Frontières' [2012] 5(1) Public Health Ethics 58

[87] Ibid 58

[88] The Nobel Prize, *The Nobel Peace Prize 1999* (1999)

[89] Charles J. McFadden, *Medical Ethics* (3rd edn. F. A. Davis Company 1953) 1

[90] Aji Markose, Ramesh Krishnan, and Maya Ramesh, 'Medical Ethics' [2016] 8(5) Journal of Pharmacy and Bioallied Sciences 1

and nurses towards the patient. This also includes the rest of the health care facility, as well as other health professionals and society.[91]

Generally, medical ethics means that medical professionals must provide services to humanity with complete respect for dignity of the profession and humans. Thus, financial gain or rewards is a subordinate concern. Medical ethics are commonly built on four pillars of basic principles: autonomy, i.e. the patient's autonomy of thought, intention, and action with regard to their health care; justice, i.e. the burdens and benefits of treatments must be distributed in equal manners among society; beneficence, i.e. conducting procedures with intent to benefit the patient; non-maleficence, i.e. conducting procedures that will not harm the patent or others.[92]

## 2.3      The responsibility of humanitarian actors

International humanitarian law (IHL) implementation is essentially based on the respect by combatants for the specific obligations and laws, particularly with regards to the protection of civilians during conflicts as well as respect towards the work of humanitarian organizations.[93] Furthermore, instead of depending on postmortem justice, the first concern of humanitarian law is to reduce the consequences of violence. Thus, the Geneva Conventions as well as their Additional Protocols have provided a crucial steppingstone to humanitarian organizations. Meaning that humanitarian actors are enabled to negotiate and implement relief activities in correspondence with the rights of the victims and humanitarian principles.[94]

In accordance with IHL, humanitarian organizations have (inter alia) the right to:
- at any time, offer their assistance to parties to the conflict. That is, without the risk of being interpreted as interfering with the States domestic affairs;
-  verify that there is no suffering as a result of excessive hardship based on a deficit supply of essentials for survival – i.e. medical supplies and food;
- overall assist through means of relief action when populations suffer from shortages of such essentials, and subsequently monitoring the distribution;

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[91] Ibid 2.

[92] Martin H. Johnson, 'The medical ethics of paid egg sharing in the UK' [1999] 14(7) Human Reproduction 1912

[93] Françoise Bouchet-Saulnier, *The Practical Guide to Humanitarian Law* (2nd edn. Rowman & Littlefield Publ. 2007) Médecins Sans Frontières

[94] Ibid

- assist and care for the sick and wounded, as well as ensure that the treatment is in compliance with medical ethics and equality;
- ensure that displaced or detained persons are able to claim their right of protection and assistance;
- provide assistance to all protected persons in line with the rights and protections guaranteed by humanitarian law.[95]

Despite being a global medical humanitarian actor, MSF ultimately does not hold a status of a formal institution. It much rather is a civil society organization with takes root in its action based on impartiality, neutrality, and independence. Though being described as a humanitarian organization, it does not necessarily mean it is bound by IHL per se – that is, in the same way as States or other parties to the conflict. Kate Mackintosh found that 'The Geneva Conventions [do not] confer rights or impose obligations upon humanitarian agencies. The Conventions simply do not address these actors'.[96] Still, as medical organizations generally work in zones of conflict in which IHL apply. Naturally, MSF abides the conditions following IHL as a result. Furthermore, MSF is able to benefit from complying with and respecting the establishment of IHL – for instance in terms of operational spaces and access to patients.[97]

As a result, the responsibility and duty of protection for victims of armed conflict does not only lie with parties of the conflict. It also dependent on the impartiality and professionalism of humanitarian organizations – in accordance with the Geneva Conventions.[98] However, humanitarian organizations are not imposed strict legal obligations that could result in penal sanctions according to the 1949 Conventions, as well as their 1977 Additional Protocols. Thus, by having a strong active humanitarian presence as well as a patient-based approach, MSF is responsible for patient relief, in addition to negotiating working conditions with belligerents.[99] In order to provide patient relief in crisis, MSF must subsequently ensure access to health services based on impartiality, neutrality and independence.

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[95] Ibid. See also e.g.: The First Geneva Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field (1949) 75 UNTS 31 art. 9; The Fourth Geneva Convention relative to the Protection of Civilian Persons of Time of War (1949) 75 UNTS 287 art. 4

[96] Kate Mackintosh, 'The Principles of Humanitarian Action in International Humanitarian Law. Study 4: The Politics of Principles: the principles of humanitarian action in practice. HPG Report 5' (2000) 4

[97] Ibid

[98] Bouchet-Saulnier (n 93)

[99] Bouchet-Saulnier (n 93)

# 3 The importance of inclusion of persons with disabilities in humanitarian action

Even though PWDs obtain status as the world's largest minority, humanitarian actors struggle to provide sufficient and inclusive health services to this group. And as a humanitarian medical emergency organization, MSF holds a responsibility to ensure that *all* people can access their health services – particularly people belonging to vulnerable groups. Moreover, as a result of how MSF's activities predominantly occur in low-income countries, the potential failure of excluding PWDs corresponds with dismissing nearly 20 per cent of the population.[100] In addition, although MSF have the means and capacity to ensure and provide health services to PWDs, it does indeed require a level of awareness as well as deliberate focus through proven and sufficient methods.

Furthermore, a recent global study conducted by the World Humanitarian Summit found that during a humanitarian crisis, 75 per cent of the participants with disabilities were not able to access appropriate basic assistance.[101] This included access to water, food, shelter, education or health services. In addition, the study highlighted that half of the participants with disabilities did not have access to services specific to PWDs. The first of the two following sections will explore the legal basis on the right to health in relation to PWDs and humanitarian action in general. The latter section will focus why inclusion of PWDs is particularly relevant and important for MSF.

## 3.1 Why focus on inclusion of persons with disabilities?

*MSF missions are carried out in respect of the rules of medical ethics, in particular, the duty to provide care without causing harm to either individuals or groups… Aiming at maximum quality and effectiveness, MSF is committed to optimizing its means and abilities, to directly controlling the distribution of its aid, and to regularly evaluating the effects.*[102]

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[100] World Health Organization (n 1) xi

[101] World Humanitarian Summit, 'Inclusion of persons with disabilities into humanitarian action: Special Session Summary Core Responsibility Three of the Agenda for Humanity' (2016)

[102] Médecins Sans Frontières, *WHO ARE THE MEDECINS SANS FRONTIERES* (n.d.) 3

As a group, PWDs are often vulnerable and require the same amount of medical attention (or more) as the general population. And as a medical humanitarian organization, MSF has a particular responsibility to target the most vulnerable groups – especially in low-income countries where the prevalence of PWDs is high. Furthermore, PWDs are often stigmatized throughout their lives – much related to taboos resulting in exclusion, marginalization and trauma. Ultimately, this occasionally results in complete abandonment. Moreover, as conflicts, emergencies and disease outbreaks simply does not discriminate, but rather affect everyone, PWDs are especially at risk.

Although diseases and illness are the most common element of a disability, conflict and war has become a more common cause in later years. Even though it is not only limited to the direct physical threat of conflict, the consequences of war and its impact on infrastructure, access to nutrition and healthcare, also results in injury, impairment and disability. Indeed, it is estimated that for every child that is killed in warfare, three acquire a disability.[103] Thus, an overall deteriorating environment not only causes, but also pose a major risk to PWDs.[104]

It is important to note that although PWDs are often described as one of the most marginalized and vulnerable groups in society, it is not necessarily on an individual level, but also a result of social constructionism. Meaning that usage of the term 'vulnerability' may refer to a factor *within* the individual who has a disability.[105] I.e. PWDs are not inherently vulnerable, however often perceived as vulnerable as a consequence of global inequalities. Ultimately, this issue could be remedied through measures of policies and practices with intent to produce equitable standards of living.

Nevertheless, due to marginalization, PWDs are among the most vulnerable in any crisis.[106] Although people with visual impairments do indeed sometimes receive the support they need, people with other disabilities are often overlooked. Particularly with regards to people with

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[103] Economic and Social Commission for Western Asia (n 36) 10

[104] Economic and Social Commission for Western Asia (n 36) 10

[105] Poul Rohleder, Stine Hellum Braathen, Mark T. Carew, *Disability and sexual health: a critical exploration of key issues* (Routledge, Taylor & Francis Group, 2018) 36

[106] Habiba Ali-Amin, *TIC Project: Inclusion of Persons with Disabilities. Newsletter #8 – Covid-19: Rethinking Vulnerability* (27 May 2020)

intellectual disabilities that generally endure the highest incidence of violence.[107] In situations of a natural disaster, disease outbreak, or other crisis', everyone struggles and find themselves stuck. However, PWDs are even more affected and at risk in these situations, and often suffer from neglect as experienced by MSF International Board Member, Habiba Ali-Amin.[108]

Still, MSF as a humanitarian actor built with a mandate and philosophy to help those who need it the most, one must also consider the pragmatism of focusing on PWDs to this measure. Through a moral utilitarian lens, a pragmatic understanding of both human rights as well as humanitarian aid is based on whether the consequences of action is favorable to the general and majority welfare.[109] To put it bluntly and contextualize, will proactive and extended focus on inclusion of PWDs come at the expense of maintaining patient activities as normal? By investing time, materials and resources in general, in order for MSF to appropriately fall in line ensuring inclusion of PWDs, resources must be allocated from somewhere. Ultimately, these resources would have been useful in different areas of action if the motion had not passed through the MSF international GA.

One example of this utilitarian perspective that conclusively contradict the medical ethics and guidelines of MSF, is when WHO decided to eradicate tuberculosis (TB) in the early 1990s. According to Rony Brauman, former President of MSF, the WHO program which aimed to limit the spread of multi resistant TB instructed that no patient ought to be treated unless one could expect 'an 80 percent rate of compliance from the population he belonged to'.[110] Thus essentially arguing if one is unable to reach such high levels of compliance, then it is better not to give treatment. This ultimately created a potential scenario where doctors are instructed not treat patients in order to curb the spreading – which could lead to more death.

In a similar matter, it is argued that PWDs ought to be included and ensured equality of health care – 1 billion people should not suffer at the cost of the majority. Not only because of human rights, but also focusing on the benefits and contributions of PWDs. For instance, inclusion of

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[107] 'Intellectual disabilities' referring to a person that has certain limitations in cognitive functioning and skills – often in reference to communication-, social- and self-care skills. See Special Olympics, '*What is Intellectual Disability?*'

[108] Habiba Ali-Amin (n 6)

[109] James Nickel, *Making Sense of Human Rights* (2nd edn. Blackwell Publishing, 2007) 58

[110] Rony Brauman, 'Questioning health and human rights' [2001] 2(6) Human Rights Dialogue: Rights and the Struggle for Health

PWDs benefits everyone through breaking barriers and raising awareness for all – specifically creating an accepting sphere for those with temporary disability, or people with adventitious disability (disability acquired after birth). Therefore, because the right to health is a universal right which implies to all human beings, all individuals have the right to claim it. This subsequently relates to MSF as a medical aid organization as well as being based on medical ethics. This will be discussed in the following section.

## 3.2 How does the inclusion of persons with disabilities in humanitarian action relate to the human right to health?

A legal basis is required in order to establish the universal right to health as incorporated in the Universal Declaration of Human Rights Article 25 on the right to a standard of adequate living.[111] It is further codified by Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.[112] Furthermore, the right to health is acknowledged by the UN Committee on Economic, Social and Cultural Rights (CESCR) through General Comment 14 on the highest attainable standard of health within this context.[113] Thereinafter, the following section will discuss scenarios of when national health structures fail to maintain its obligations on the right to health, and the subsequent responsibility of humanitarian actors to address this gap.

Similar to other economic, social, and cultural (ESC) rights, the right to health is a necessary requirement in order to achieve other civil and political freedoms and entitlements, as well as economic and social ones.[114] Nevertheless, even though all States aim to have a healthy population, they are simultaneously watchful of devoting extensive parts of their GNP in health-related matters. That is, namely due to the spiralling expenses of health care.[115] As a consequence, several nations have resorted to private health institutions and provisions in order to

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[111] Universal Declaration of Human Rights (adopted 10 December 1948), UNGA Res 217A (III) (UDHR) Art. 25

[112] ICESCR(n 3)

[113] CESCR, *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, UN Doc E/C.12/2005/4 (11 August 2000)

[114] Ilias Bantekas and Lutz Oette, *International Human Rights: Law and Practice* (2nd edn. Cambridge University Press 2016) 429

[115] Ibid 429

reorganize public wealth to other sectors of interest. Naturally, the issue occurs when health care becomes unaffordable for some, resulting in ill health or loss of life.

The aforementioned art. 12(1) of the ICESCR provide the right to the highest attainable standard of health for everyone. Thus, it does not guarantee the right to be healthy – as that would be an impossible pledge, even so with the best medical care and attention.[116] Still, the Covenant acknowledges the right's representation as a proposition that is broadly dependent on the positive obligations of States. On the one hand, these obligations require arrangement of adequate health care services. On the other hand, however, it additionally obliges the State to uphold the socio-economic basics of health: primarily, food and water, shelter, sanitation, disease prevention and more.[117] Nonetheless, neither the ICESCR nor the CESCR demands that health care and its subsequent components to be free.

Indeed, the CESCR put emphasis on the affordability, availability, and equality of health services.[118] At the first level, affordability must be contingent on the material capacity of a person to live a life of dignity. Thus, the State must offer free health care if a person is not able to pay for their own medical treatment or other socio-economic fundamentals, in order to prevent the loss of a dignified life. To exemplify, through the *Treatment Action Campaign* in South Africa, the South African Constitutional Court found no reasonable basis to deny a drug that could prevent HIV transmission from mother to child.[119]

At the second level, all three factors of affordability, availability, and equality is of crucial essence as pharmaceutical companies continue to protect their patented drugs at extreme prices in a monopolised market. For instance, in States where poverty is prevalent, national courts continuously attempt to create legal arguments in order to obstruct the patents and the exclusive rights that pharmaceutical companies often obtain. The Indian High Court is one example, where they have a preventative system that allows for licensing of generic drugs by non-patent holders.[120] Essentially earning the title as "pharmacy of the developing world".[121]

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[116] Ibid 429

[117] Ibid 429

[118] CESCR (n 113) para. 12

[119] *South African Minister of Health v. Treatment Action Campaign* (TAC) (2002) 5 SA 721 (CC)

[120] *Bayer Corp and Another* v. *Union of India and Others* (2010)

[121] Mihir Mankad, 'India: 'The Pharmacy of the Developing World'' *Save the Children* (16 February 2015)

As addressed in earlier sections, States have generated a risk of health exclusion in terms of affordability, availability and discrimination. This is often related to, however not necessarily, as a result of a totalitarian and authoritarian rule. Thus, potentially resulting in severe socio-economic and political impacts for the general public or certain groups of civilians.[122] Moreover, when situations like these escalates, there is often a high risk of loss of health care – and in the most extreme (though unfortunately not rare) circumstances, loss of life. As a consequence, humanitarian actors act to fill the gap in order to ensure health access and services.

These gaps are not only created through official oppressive governance, but it can also occur under various of circumstances. The right to health can also denied, neglected, ignored, or based on factors of affordability, availability, or discrimination, during civil war, disease outbreak, natural disasters, and more. Humanitarian actors and medical aid organizations that work within these contexts require mandates and guidelines of action in order to maintain international as well as national laws and directions. If not, the organization risk eviction and banishment from country of mission or project. This was the case in 2013, when the governments of Ecuador and Bolivia shut down or evicted NGOs working on matters of environment, extractivism, and indigenous rights.[123] The ground for evictions was conspiracy against the state.[124]

There is obviously a fine balance between the NGOs social mission and respecting national legislation and statutes. It is therefore absolutely crucial and evident that NGOs attempt to maintain a certain level of impartiality and neutrality in field missions and projects. Specifically, as a medical organization, MSF contributes to fill the health gaps, and subsequently conducts their social mission through a high held basis of medical ethics in this context. As part of its social mission, MSF's mandate highlights the importance of maintaining impartiality, neutrality, and independence. Thus, arguing that MSF, as an international humanitarian actor, has a responsibility to ensure inclusion of PWDs in field missions and projects. That includes, in particular, seeking out those who are unable to access their health services.

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[122] E.g. (in recent time) Muslims in Myanmar; civilians in Libya; civilians in Venezuela.

[123] See both Bret Gustafson, 'Close the NGOs: Asserting Sovereignty or Eroding Democracy?' *NACLA Reporting on the Americas since 1967* (31 December 2013); William Neuman, 'U.S. Agency Is Expelled From Bolivia' *The New York Times* (1 May 2013)

[124] William Neuman, 'U.S. Agency Is Expelled From Bolivia' *The New York Times* (1 May 2013)

# 4 How can persons with disabilities sufficiently be included in MSF projects?

Access to medical health care is a universal right, a right that is established in and protected by several international human rights conventions and declarations.[125] This right is fulfilled daily by people who are able to benefit from competent and advanced health care systems, often funded by the nation's government (e.g. NHS in the UK). Nevertheless, equitable health care continues to be a distant realization for many.[126] Particularly people living in low-income countries, or poor areas in high-income countries, generally suffer from lower access to health services and medical care in comparison to others.[127] For instance, this could involve increased restrictions due to geographic accessibility, financial practicality, as well as availability and cultural appropriateness in order to apply and utilize medical health care.[128]

Although MSF does not have the intention to reach absolutely everyone, it does aim to be a medical aid organization without barriers. A goal most ambitious, however not unachievable. Thus, referring to its high held impartiality, it consistently works to proactively identify and subsequently remove barriers in order to ensure access to lifesaving aid for those most vulnerable. In order to properly address this, it is evident to reflect and ask, "who are the patients that do not reach MSF services?". This chapter will focus on the MSF organizational structure in order to understand the adoption of the inclusion of PWDs motion, and thus comprehend the basis for MSF engagement towards the project. Furthermore, the below sections will discuss who the patients are that do not access MSF health centers, as well as the various barriers that causing health service exclusion.

## 4.1 MSF organizational structure

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[125] E.g. UDHR Art. 25 and ICESCRArt. 12

[126] 'Equitable health care' defined here as 'equal access to available care for equal need, equal utilization for equal need [and] equal quality of care for all' by Margaret Whitehead, 'The concepts and principles of equity and health' [1991] 6(3) Health Promotion International 221

[127] David H. Peters et. al, 'Poverty and Access to Health Care in Developing Countries' [2008] 1136(1) Annals of the New York Academy of Sciences

[128] See Ibid; G. Saloojee et al. 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township' [2007] 33(3) Child: Care, Health and Development; Gert Van Rooy et al. 'Perceived barriers to accessing health services among people with disabilities in rural northern Namibia' [2012] 27(6) Disability and Society

MSF is built on a democratic foundation – meaning all board members, both national and international, are voted in by the members of each association. Through MSF associations, members can voice their opinions and further contribute to the definition and implementation of MSF's mission. As a result, the associations assure the identity of MSF, and ensure that both the activities and operations is in correlation with MSF's Charter, principles and social mission.[129] All MSF association members are current or former MSF employees or volunteers in MSF headquarters or field missions. The below illustration presents the current MSF Association, along with color-codes displaying with operational center each association belong to.

It is through this organizational structure that the motion on PWD inclusion was presented. Through the various levels of General Assembly's (GA) – first, through the joint Norwegian and Swedish GA, then the International GA, and finally adopted at the highest level by the International Board – the motion eventually adopted throughout MSF. During the joint GA of Norway and Sweden, the final voting results was: 137 – yes, 7 – no, and 6 – abstentions. Furthermore, it won the majority vote on all MSF levels, although it was indeed thought to be

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[129] See Médecins Sans Frontières internal website: InsideOCB, *About the Association* (n.d.)
[130] See ibid

similar to a preceding TIC project on diversity, equity and inclusion project prior to being sub-mitted.[131] In addition, concerns were raised with regards to what will happen to PWDs after certain MSF projects ends. However, there are clear examples of cooperation between MSF and other organizations in field projects – with particular focus on PWDs.[132] Therefore, due to its particular focus on PWDs, it was a welcomed step of progression throughout the movement and in line with MSF principles.

The motion to promote disability inclusion in MSF was presented, voted on, and finally adopted, based on the following text:

> *Recognizing that persons with disabilities are often the most in need in regions where MSF works and that their exclusion may hamper our humanitarian identity and impartiality, MSF should:*
> - *Initiate actions to develop its awareness on the risk of exclusion of persons with disabilities,*
> - *Develop dialogue with organizations of person with disabilities where/when possible,*
> - *Take in account accessibility to persons with disabilities of our facilities and of our communication materials[133]*

### 4.1.1 The rationale behind the motion

According to motion instigator, Patrice Vastel, the need to set particular focus upon PWD inclusion was ultimately a result of vague ignorance and neglect. By that it is meant that MSF fieldworkers and staff was unable to touch much on the subject as there were almost no patients to represent the PWD community at MSF health services. Indeed, in accordance with field-workers' observations, there were and still is a general absence of PWDs in field missions and projects. Thus, arguing that as approximately 15 per cent of the population has some sort of

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[131] Interview with Patrice Vastel, Coordinator of project on inclusion of PWDs in MSF, Médecins Sans Frontières (Oslo, 29 April 2020); See also: Médecins Sans Frontières Transformational Investment Capacity, *Phase II PRV – Diversity, Equity and Inclusion* (n.d.)

[132] For instance, through a reconstructive surgery project in Jordan, see Médecins Sans Frontières, *Reconstructive surgery hospital Amman – Jordan* (2017) See also: Unni Karunkara and Frances Stevenson, 'Ending Neglect of Older People in the Response to Humanitarian Emergencies' [2012] 9(12) PLoS Medicine 1,2

[133] Vastel (n 14)

disability, there ought to be a definite presence of PWDs at health centers and hospitals accordingly. I.e. if MSF does not actively seek out PWDs, then they remain an unseen group of patients with little chance to access health services.

What, then, is the reason why PWDs are not visible for MSF in the field? Some of the rationale behind the absence of PWDs is arguably due to the various barriers that affect the lives of PWDs – especially in low-income countries. These barriers will be explored in later sections. Still, MSF International Board member, Habiba Ali-Amin, argues that it is a result of an unconscious bias which affect the ability to be sensitive towards minorities such as PWDs.[134] Thus, during construction of MSF facilities, measures of inclusion are not met. There are no slopes, or door- and hallway adaptations for wheelchair users. Accessibility of line areas, waiting areas, or service counters is not prioritized. Inadequate availability of audio and visual information for blind and deaf individuals. Wash and Sanitation (WASH) teams fail to consider latrines for individuals with physical impairments. Nor is there courses and trainings in order to challenge the attitudinal unconscious biases. Although this highlights the severity of excluding PWDs to claim their right to health, it is important to acknowledge the role of counterparts through local DPOs and the knowledge they possess. Especially in order to help break the abovementioned barriers.

## 4.2 Who are the patients that do not access MSF services?

As an organization, MSF does not have the intention to reach everyone. It does, however, have a responsibility as a humanitarian actor to have the ambition and aim to seek out the most vulnerable groups. Thus, persons with disabilities require particular focus in order to uphold and maintain these organizational standards – especially as PWDs are 'disproportionately affected in situations of risk and humanitarian emergencies, and face multiple barriers in accessing protection and humanitarian assistance, including relief in recovery support'.[135] In field missions and projects, MSF are often located in remote areas with limited access to adequate road construction, electricity and water. Consequently, access to health services needs to be a priority in the processes project locations. That is, essentially asking and thus defining: who are the

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[134] Ali-Amin (n 106)

[135] Charter on Inclusion of Persons with Disabilities in Humanitarian Action (2016) para 1.7

potential patients that are unable to access our services, and how can we ensure all patients access this health facility?

As disabilities can be both temporary and permanent, field projects must continuously work to adapt and create a flexible service that allows for inclusive access to health services. Patients who do not access or are especially challenged to access MSF health services include, but do not exclude, individuals: with visual and hearing impairments; various mental and physical conditions; and intellectual disabilities. Some of these disabilities are permanent, and some are temporary – i.e. pregnancy. Although the following factors are not defined as a disability, they do impact peoples' right to health due to local socioeconomic and cultural characteristics. For instance, biological discrimination contributes to limited access to health services for girls and women. Furthermore, due to religious and cultural exclusion, members of the LGBTQI+ community is also denied appropriate health access. Financial factors are also a considerable reason for health care shortage. This ought to be mentioned as this context addresses the right to health for those most vulnerable.

## 4.3    What are the barriers which hinder persons with disabilities to access MSF services?

As aforementioned, there are several categories of barriers that affect PWDs globally – however, they are particularly afflicted in low-income countries where MSF have their primary operational activities. The barriers have an excluding and distressing impact often resulting in denied access to health services, and direct violation of the right to the highest attainable standard of mental and physical health. Although the standard is subjective and depends on the standard of living as well as individual countries and health services, most areas in which MSF obtain operational activities are areas where PWDs are neglected and not prioritized.

A medical humanitarian organization based on the principles of independence, impartiality and neutrality, must give priority to the most urgent cases – regardless of nationality, race, gender, class, religious beliefs or political opinions. As a result of disasters, conflict and displacement, the effectiveness of humanitarian action is challenged with facing multiple barriers. People in general, however PWDs in particular, are often confronted with attitudinal, environmental and institutional barriers impacting their access to healthcare, as well as participation and full

enjoyment of rights.[136] Although one can be excluded as a result of multiple barriers simultaneously, PWDs are not a homogenous group and are therefore also impacted differently by barriers. Various barriers in combination with different types of disabilities as well as different environmental circumstances, ultimately result in a variety of experiences related to exclusion. Moreover, despite actions of impartiality and neutrality, intersecting identities also impact the level of exclusion in relation to barriers – e.g. gender, age, ethnicity and sexual orientation.

First, the impact of attitudinal barriers includes prejudice, discrimination, and stigmatization of PWDs. In practice, this involves preconceived notions and social constructions about the needs and limitations of PWDs in society. A common and consistent example of an attitudinal barrier and how PWDs are excluded from health services, are in matters of sexual and reproductive health. Naturally, research consistently confirm that PWDs engage in sexual activities and subsequently require sexual and reproductive health care services.[137] Essentially disregarding the myth that PWDs have diminished sexual need or are asexual.[138] Particularly as sexual abuse affect PWDs disproportionately in comparison to the general population, sexual health and education is of definite essence.[139]

Still, as with many other aspects of society, PWDs are partially and frequently excluded from such services.[140] Due to the social constructions relating to our ideas, notions and thoughts about sexuality and sex, many consider it to involve power and control. Moreover, there are preconceived attitudes towards who ought to have sex with whom; why people should have sex and how; and, when and where people should have sex.[141] Much of such myths particularly affects people with physical disabilities or people with learning (intellectual) disabilities. Primarily due to the perception that people with physical disabilities are asexual because others regard them to have absent sexual needs, to be physiologically unable to have sex, or be too inadequate to

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[136] Humanitarian Advisory Group (n 5) 2

[137] See Lena Jemtå, KS Fugl-Meyer, K Öberg, 'On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairments' [2008] 97(5) Acta Pædiatrica; Taiwo M. Oladunni, 'Sexual Behavior and Practices Among Adolescents with Disabilities in Southwest Nigeria' [2012] 30(3) Sexuality and Disability

[138] See Shaniff Esmail, Kim Darry, Ashlea Walter, Heidi Knupp. 'Attitudes and perceptions towards disability and sexuality' [2010] 32(14) Disability and Rehabilitation; Maureen S. Milligan and Aldred H Neufeldt, 'The Myth of Asexuality: A survey of Social and Empirical Evidence' [2001] 19(2) Sexuality and Disability

[139] Rohleder (n 105) 50

[140] Ibid 74

[141] Ibid 23

engage in sexual activities.[142] Much of these perceptions are based on the view that PWDs are "forever children" – i.e. not consenting individuals with adult bodies, alongside sexual desires and needs. [143]

Related to this instance, Anne Finger (a disabled woman with a physical disability), specified that 'sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain'.[144] Essentially pointing out how the stigmatization of disability and sexuality may lead to further exclusion in matters of sexual and reproductive health. Bringing this example into the context of MSF, PWDs can be excluded in general health check-ups – and especially in sexual health screenings.[145]

Second, environmental barriers primarily concern communicative barriers as public transport, public information systems, and access to hospitals and schools. The environment that holds the context and operations is absolutely evident in order to determine the ability to practice inclusive measures and action – i.e. one size does indeed not fit all. In this regard, environmental barriers impact the PDW's ability to reach, enter, use, or circulate within physical spheres.[146] To *reach* include accessibility through infrastructure, i.e. roads and terrain, as well as access to mobility devices. MSF often work through mobile clinics in areas with rough terrain. Through actively reaching out to remote areas by motorcycle or boat, health personnel are able to access people and patients despite inadequate roads, or the capability or the capacity of the patient to access health services.[147]

To *enter* highlights the importance of having large enough doorways and steps. In the context of MSF this could relate to the construction of hospitals and health services, e.g. ensure that doors and toilets are adapted to wheelchair users. Another example is to enable both blind and deaf to physically feel or see the entrance of the health clinic, as well as easily maneuvering once inside (which ultimately relates to the *circulate within* module). To *circulate within*

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[142] Ibid 23

[143] See Ann Craft, *Practice Issues in Sexuality and Learning Disabilities* (1st edn. London Routledge 2004)

[144] Anne Finger, 'Forbidden Fruit: why shouldn't disabled people have sex or become parents?' *New Internationalist 233* (July 5, 1992)

[145] Interview with Patrice Vastel (n 131)

[146] Humanitarian Advisory Group (n 5)

[147] E.g. Médecins Sans Frontières, 'Isolated or forgotten, MSF mobile clinics reach remote populations in Colombia' (2003)

includes the hallways and room space, essentially maintaining the inclusive standards that were met upon entering.[148] In MSF projects this includes having large enough hallways and room space, however also having sustainable options for stairs in line with wheelchair users or others for instance. To *use* ultimately refers to the including measures of obtaining an appropriate table height, as well as toilets and sinks.[149] It also includes measures of tactile paving for blind people, sufficient visual and audio information, as well as available information for functional illiterates.

Furthermore, according to Vastel, one of the most substantial barriers is considered to be an environmental barrier of transportation.[150] For instance, this includes public transportation that are not practically adapted to the needs of a person reliant on a wheelchair, or does not have visual and audio information systems adapted to blind and/or deaf persons. Furthermore, exclusive transportation systems can also be an institutional barrier – meaning that the public sector ought to build public roads that access remote areas.

Thirdly, institutional barriers concern employment- or educational-based exclusion. This barrier is often a result of laws, policies, strategies or practices that ultimately discriminate against PWDs.[151] Although the exclusion might not be intentional, systems still discriminate PWDs by not including them and their needs. For instance, a study of five Southeast Asian countries showed that electoral laws failed to specifically protect the rights of PWDs.[152] The study also found that 'some banks do not allow visually impaired people to open accounts, and HIV testing centers often refuse to accept sign language interpreters due to confidentiality policies'.[153] Furthermore, many countries still obtain strict restrictive laws that especially impact individuals with psychosocial or intellectual disabilities.[154]

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[148] Red R UK and ADCAP, 'Inclusion of Age and Disability in Humanitarian Action: a two-day training course' (2017) 42

[149] Ibid 42

[150] Interview with Patrice Vastel (n 131)

[151] World Health Organization and The World Bank, 'World Report on Disability' (2011) 6

[152] The Center for Election Access of Citizens with Disabilities (PPUA Penca), 'Accessible Elections for Persons with Disabilities in Five Southeast Asian Counties' (2013) 5

[153] Lorraine Wapling and Bruce Downie, 'Beyond Charity: a donor's guide to inclusion. Disability funding in the era of the UN Convention on the Rights of Persons with Disabilities' (2012) 21

[154] Kathy Al Ju'beh, 'Disability Inclusive Development Toolkit' (2017) CBM 88

In order to change the institutional barriers of excluding laws, policies, strategies or practices, there is a need for both political support and enforcing mechanisms. For instance, a study of Norway's work of PWD inclusion in development and humanitarian action reported that policies on inclusion have indeed been ignored, or at best forgotten.[155] The evaluation also found that issue of disability has not been a prioritized political matter for the Norwegian government, ultimately revealing both ineffective mainstreaming, weak advocacy, and lack of coordination.[156]

For MSF, institutional barriers relate to their patient-based approach, thus impacting the organizational policies, strategies and practices. Furthermore, institutional barriers are essentially a literal factor of how the motion on inclusion was brought through. Meaning that by using the system in place, there was an opportunity to change and improve the institutional structure. I.e. by identifying the issue and the barriers on inclusion of PWDs in MSF, Patrice Vastel was ultimately able to create organizational and institutional change through MSF policies, strategies and practices. The following chapter will address the matter of attitudinal-, environmental- and institutional barriers in depth.

## 5    How does MSF work to include persons with disabilities in field missions and projects?

The 'TIC project on Inclusion of People with Disabilities' in MSF was a result of an international motion that was broadly supported through the associative channels of MSF. Post its adoption, the motion continues to use the associative spirit of MSF members to encourage ownership in order to make the matter of PWD inclusion an issue of their own.[157] As a result, the process of transforming MSF is based on the broad comprehension that it requires commitment through associative members and colleagues to essentially pick up the ball and pass it forward.[158]

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[155] Norad, 'Mainstreaming disability in the new development paradigm: Evaluation of Norwegian support to promote the rights of persons with disabilities' (2012) 85

[156] Ibid 59

[157] Médecins Sans Frontières TIC project Inclusion of Persons with Disabilities, *TIC Project: Inclusion of Persons with Disabilities Newsletter #4 – A warm welcome* (04 February 2019)

[158] Ibid

Previously, it was established that MSF continuously work in order to comply with its principles of impartiality, neutrality, and independence. This entail receiving low – or none – governmental funding, not taking any active standpoint or side in conflicts, and having operational activities where MSF see the highest need. The MSF principles and identity has high prevalence throughout the organization and among its staff, essentially creating a basis for its patient-centered medical humanitarianism. That is, helping those who need it the most – including vulnerable groups, and PWDs in this context. Nevertheless, the organization actively pursue reflections and views that have a critical view of the organizations work and priorities. This include establishing a democratic organizational structure with a general assembly, which enables all members' voices to be uttered and opinions raised.

## 5.1     To what extent has MSF established inclusive structures?

In order to ensure PWD inclusion in field missions, MSF has identified and adopted six keys. These are: (1) learn and raise awareness; (2) the use of a "universal design" for construction of facilities; (3) accessible communication (i.e. audio and visual); (4) reach out to disabled people's organizations (DPOs); (5) focus on recruitment of PWDs; and (6) include concerns of and for PWDs in assessments and project process.[159]



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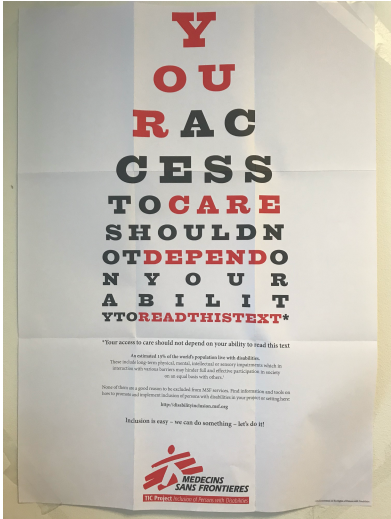
[159] Médecins Sans Frontières, 'Inclusion of Persons with Disabilities. 6 keys for inclusion in MSF missions' (2016)

[160] Poster located in MSF Norway office. Frequently used during PWD inclusion workshops.

The first key challenges the main barrier to inclusion, i.e. attitudinal barriers. The negative attitudes towards PWDs are often related to wrongful assumptions, prejudices, stigmas and beliefs. Thus, by raising awareness and learning about the risk of exclusion, field workers will be able to increase inclusion in practice in MSF field missions and projects. In order to address this key, field trainings and courses is provided globally.[161] These focus on sensitization on inclusion and how to essentially create transformation in MSF projects. During trainings, PWDs also shared their personal experiences, as well as guiding the group through different activates and group exercises to create awareness. The activities and exercises included sitting in a wheelchair while presenting, searching for their seats while blindfolded, or having a conversation while not being able to hear. Ultimately, the next step of the first key is for the participants to engage in inclusion and to spread the message through the learned exercises.

The second key identifies the physical need of establishing inclusive constructions and facilities by adopting a "universal design" – i.e. environmental barriers.[162] Not only is it more cost-beneficial to build facilities that encompass an accessible design, than to adapt them later. A universal design is access to healthcare in practice – i.e. promoting slops, adapting toilets and doors, and ensuing free passages. Nevertheless, if built with excluding measures, one can take the opportunity after a natural catastrophe to re-build facilities in a more inclusive and accessible manner. The third key promote the importance of always using two ways of communication – audio and visual. In order to communicate with a broader audience, MSF staff are encouraged to always inform and reach out through visual and audio – i.e. text and sound. Particularly during awareness-raising campaigns in the field. This could also relate to ensuring that there is a local translator available, or individuals who are able to communicate through sign language.

The fourth key highlights the significance of contacting and collaborating with DPOs, especially locally. This key relates namely to all three categories of barriers, meaning that by reaching out to local DPOs, humanitarian actors will be able to critically analyze their structures and adapt to local needs. DPOs can offer valuable insight in order to evaluate how MSF support

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[161] Interview with Patrice Vastel (n 131)

[162] "Universal design" is a term used to address and create inclusive products, environments, programs and services for PWDs to the greatest extent possible. However, by using the term "universal", emphasis it put on the intention of disregarding specialized design with regard to PWDs – it should simply be adaptable if needed. See Médecins Sans Frontières TIC project Inclusion of Persons with Disabilities, *TIC Project: Inclusion of Persons with Disabilities Newsletter #2 – Make inclusion a reality* (2018)

facilities and health services, and subsequently make it increasingly inclusive for PWDs. Furthermore, DPOs can use their network to reach PWDs and communicate information about health services as well as job offers – both during and after MSF projects. Considering that MSF have a high prevalence of local employees in field missions, this is an important inclusive communication channel and the movement has been provided with tools to easily engage with DPOs.[163]

The fifth key builds on the fourth key, though it is less patient-focused and more centered towards recruitment of field personnel. This key also relates to overcome institutional barriers to subsequently ensure inclusion through employment and education, as well as to overcome attitudinal barriers. In order to challenge the prejudice of PWDs with regards to what they can and cannot do, the fifth key encourage recruitment of PWDs. In addition to working for MSF, fieldworkers with disabilities can increase understanding and awareness among their colleagues. Moreover, they can additionally offer particularly rare skills, e.g. sign language. This key is perhaps the easiest to implement as well – simply by stating that 'persons with disabilities are encouraged to apply'.

The last and sixth key is an overall focus on PWD inclusion in assessments and projects, which ultimately relate to all three barrier groups. Due to the keys' comprehensive nature, as well as necessary application and involvement, it correlates with attitudinal-, environmental- and institutional barriers. It is attitudinal due to how projects and assessments are essentially based on human decision-making, thus creating a level of dependency upon the awareness of executives. The environmental aspect comes into play as field assessments and projects are heavily influenced by the particular context of each mission in term of physical character – both natural and constructed. Naturally, it also relates to institutional barriers because local laws, as well as both local and organizational policies, strategies and practices will impact the working structure. Meaning that inclusion should be a general aim during projects and assessment phases from start to finish, including specific analysis' and measures to ensure this.

Although the all six keys are both comprehensible and achievable, there has been concerns raised regarding the fifth key. According to Project Coordinator Patrice Vastel, feedback from collages disclose that it is sometimes difficult to understand why it is important to actively

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[163] Médecins Sans Frontières, *Organizations representative of persons with disabilities* (n.d.)

encourage recruitment of PWDs.[164] Vastel explains the reason simply: 'inclusion of patients with disabilities at the project level is better achieved if MSF becomes a more inclusive organization overall'.[165] Moreover, it relates to the first key of raising awareness and challenge prejudice about PWDs and the assumptions made to what they can or cannot do. As aforementioned, in addition to being fully qualified for the job, PWDs can add additional skills in terms of language, knowledge and experience in order to better understand the needs of PWDs, and thus better include them.

Furthermore, even if the employee does not obtain any contextual additional skills, the outright presence of a PWD in an MSF workforce will attract other PWDs to MSF. By actively encouraging PWD recruitment, MSF shows that the organization aim to be more inclusive, as well as that other PWDs do not have to be alone in order to tear down barriers. Thus, in order to ensure inclusion of PWDs in MSF missions and projects, both organizational change and awareness raising is evident at all levels.

In an interview with Tamara Saeb (Head of Communications, MSF United Arab Emirates), Louise Limela (Association Coordinator in DR Congo) shared her experience of being employed and working for MSF with a disability.[166] Although she admits that she was afraid of not being accepted in the hiring process based on her condition, she was ultimately hired to fill the position. In accordance with the fifth key on inclusion, Limela highlights the importance of addressing and encouraging people with special needs to apply in job vacancies. To quote directly: 'they [PWDs] may be limited in one capacity, but have experience in another'.[167]

## 5.2 Case study: PWD inclusion in MSF's response to Covid-19

For people with disabilities, barriers of attitudinal-, environmental- and institutional components still apply, however there are additional barriers. As already established, PWDs as a group is both extremely vulnerable and often forgotten in humanitarian contexts. The Covid-19 pandemic has affected everyone – regardless of being a person with disability or not. Nevertheless,

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[164] Médecins Sans Frontières TIC project Inclusion of Persons with Disabilities, *TIC Project: Inclusion of Persons with Disabilities Newsletter #5 – Voices from the field* (11 April 2019)

[165] Ibid

[166] Tamara Saeb, Interview with Louise Limela, Association Coordinator MSF DR Congo (February 2019)

[167] Ibid

PWDs and elderly people are particularly at high risk due to a high level of stigmatization – especially in the majority of contexts in where MSF have operational activities.

### 5.2.1 Challenges to public health strategies

PWDs with who have difficulty with vision or hearing, and even cognitive abilities, can struggle in order to find accessible information – especially information that is continuously changing.[168] Many public health measures put in place in response to the pandemic are discriminatory towards PWDs. In spite of a global information overload, nothing or little is appropriately adapted to the needs of PWDs. A clear-cut example of the difficulty and subsequently excluding measures as a result of Covid-19, is the requirement to wear face masks. In the many places that this required, people with hearing impairments suffer from the limitations of communication as there are often reliant on lip reading. The majority have yet to see a face mask that is both transparent and breathable.

Furthermore, Covid-19 has proven to come with a huge stigma as well. Thus, when related to PWDs, the disease creates a stigma among individuals who are already stigmatized for life. Many PWDs are dependent on the help of others for physical support – which creates a challenge due to necessary social distancing measures. This especially affect PWDs who require daily hygienic or nutritional assistance. In addition, videos of handwashing procedures only show people without physical disabilities exclusively – simply disregarding people that are unable to rub their hands together.[169] Moreover, both water and soap are often a luxury and therefore unavailable in many contexts, thus creating an economic challenge to both abled and disabled peoples. In addition to affecting nutritional and hygienic structures, social distancing also influence mental health as it can potentially deepen anxiety and isolation.

Another challenge is the worsened overall equitable access to health care. This extends from actually being tested of Covid-19, to being examined in an emergency room.[170] Many health care centers have promoted drive-up testing, which could potentially be impossible for a disabled person who rely of mobility services. Furthermore, situations of testing and examinations

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[168] John Hopkins University, *Covid-19 poses unique challenges for people with disabilities* (April 2020)

[169] Médecins Sans Frontières (n 106)

[170] John Hopkins University (n 168)

also relate to communicative barriers as protective equipment (e.g. face masks, gloves etc.) can create alienating circumstances.

## 5.2.2    How has Covid-19 impacted MSF inclusion of PWDs?

Both during prevention and in response to the Covid-19 pandemic require focus on inclusive measures. In order to limit the risk of exclusion relating to information and awareness, as well as access to health care, an inclusive approach is ensured through methods of critical assessment. That is, continuous evaluation of the accessibility of information sharing and identifying barriers that corresponds with the needs of PWDs. Thus, while maintaining and increasing a patient-centered focus and community approach, MSF have made progress towards inclusion through measures of communication (sound and text) and DPO outreach. Particularly in phases of preparation, DPOs provide essential tools to channel ways of communication towards PWDs, however also with regards to other groups and minorities.

Through a patient-based approach to humanitarian action, MSF aim to overcome all barriers and break all obstacles to identify needs during field missions – also beyond the aspects of physical appearance. In this manner, Covid-19 has changed the ways of how MSF conduct assessments and exploration evaluations. This includes both audio and visual information and increased community outreach. For instance, although the pandemic is ongoing, and there are certain limitations in terms of sufficient reporting from the field, social media platforms are reportedly used to communicate with and spread information concerning Covid-19 in Somalia and Nairobi.[171]

To further address the pandemic, MSF has engaged with the International Disability Alliance (IDA) to create a disability-inclusive Covid-19 response. The initiative identifies both barriers that PWDs face as a result on this state of emergency, in addition to some recommendations and practical solutions.[172] Overall, the document is based on global input from members of the disabled community with aim to benefit PWDs and others both on global, regional, national and local levels of advocacy. Through these measures, humanitarian actors are encouraged to focus and implement the following key recommendations:

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[171] Médecins Sans Frontières (n 106)

[172] International Disability Alliance, *Toward a Disability-Inclusive COVID19 Response: 10 recommendations from the International Disability Alliance* (19 March 2020)

1. *Persons with disabilities must receive information about infection mitigating tips, public restriction plans, and the services offered, in a diversity of accessible formats with use of accessible technologies.*

2. *Additional protective measures must be taken for people with certain types of impairment.*

3. *Rapid awareness raising and training of personnel involved in the response are essential.*

4. *All preparedness and response plans must be inclusive of and accessible to women with disabilities.*

5. *No disability-based institutionalization and abandonment is acceptable.*

6. *During quarantine, support services, personal assistance, physical and communication accessibility must be ensured.*

7. *Measures of public restrictions must consider persons with disabilities on an equal basis with others.*

8. *Persons with disabilities in need of health services due to COVID19 cannot be deprioritized on the ground of their disability.*

9. *Organizations of Persons with Disabilities (OPDs) can and should play a key role in raising awareness of persons with disabilities and their families.*

10. *OPDs can and should play a key role in advocating for disability-inclusive response to the COVID19 crisis.[173]*

Ali-Amin reports of incentives to confront mental health issues among the most vulnerable populations- both with and without disabilities (e.g. members of LGBTQI+ communities, religious minorities etc.).[174] Ultimately, the term "quarantine fatigue" is used to describe issues of exhaustion associated with the adopted restrictive steps following Covid-19. Even though the term is associated with different forms of exhaustion, symptoms may include anxiousness, changes in habits of eating and sleeping, reduced productivity and motivation, and social withdrawal.[175] In order to address quarantine fatigue measures of telecommunication, counselling and awareness raising undertake matters of self-help and anxiety – despite social distancing.

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[173] Ibid

[174] Médecins Sans Frontières (n 106)

[175] Massachusetts General Hospital, *Overcoming Quarantine Fatigue* (2020)

Furthermore, because of increased unemployment, reduced socioeconomic status contribute to a worsened situation particularly relating to access to health care – both with regards to Covid-19, however also with relevance to health services in general. Due to the consequences of the pandemic, many MSF hospitals have been converted into Covid-19 facilities and access to health care have subsequently been reduced.[176] That is both as a result of preventative and restrictive measures to prevent further infection, as well as maintaining pre-existing barriers as most facilities have failed to account for inclusive measures.

Moreover, although Ali-Amin also highlights the immense experience obtained by MSF through emergency responses, it is also argued that MSF fails to consider PWDs as part of its mission. Therefore, MSF needs to constantly analyze and commit to compromise in order to improve and adapt their emergency response. That includes appropriate assessment tools and emergency guidelines in accordance with the identified six keys. Still, Covid-19 also offer aspects of opportunity. Indeed, the unprecedented circumstances create insights to the isolated lives that some PWDs experience, and the mental health concerns associated. As the pandemic affects everyone, i.e. it does not discriminate, humanitarian actors as well as the rest of society need to grasp this opportunity to reflect and identify. Furthermore, it is also an opportunity to learn more creative ways of living as PWDs are often forced to invent conventional methods.

## 6       Conclusion

At a global level, medical humanitarian needs remain immense – particularly in low-income countries. This raises particular concern towards approximately one billion people living with some form of disability who face social, economic and cultural exclusion. These barriers are often based on attitudinal-, environmental-, and institutional perceptions and structures which could lead to restricted access to health services – thus violating the right to health. This thesis has addressed how MSF work to ensure inclusion of people with disabilities in field missions and projects. As a result of being based on the principles of impartiality, neutrality, and independence, MSF has acknowledged the need to adopt a particular focus on PWDs through its democratic organizational structure. Inclusive measures to address PWD inclusion have been

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[176] Médecins Sans Forntières (n 106)

established through medical ethics and a patient-based approach – i.e. by providing humanitarian aid based on the populations in need.

There are definite benefits and sufficient elements by adopting a RBA to implement organizational change relating to human rights practice and discourse, however MSF consider human rights to be a *universal* and inherent to humans. Therefore, MSF does not actively promote human rights as such. The organization provide humanitarian aid based on the needs of patients and medical ethics – i.e. an approach which reflects need-based and patient-centered medical humanitarianism, often associated with human rights. Ultimately, adopting a RBA can result to decreased efficiency for MSF, and it is therefore not all compatible, because the method require great resources of reporting in order to sufficiently sustain the method. If MSF was primarily a DPO, a RBA would be more appealing because it focuses on progressive politics and practices that specifically relate to particular peoples or issues.

In addition to being a vulnerable group in society, PWDs often also require more medical attention in comparison to the general population. Therefore, humanitarian actors must address their responsibility towards the PWD-community in order to maintain their commitments to the humanitarian principles of impartially and neutrality, as well as the right to health. Both the UDHR, ICESCR, and the CESCR address this right in a similar matter as to other civil and political freedoms and entitlements, as well as social and economic ones. The right to health is based on the affordability, availability and equality of health services. Still, States are watchful of devoting extensive parts of their GNP to health-related matters – primarily as a result of spiraling expenses. Consequently, private health institutions create socioeconomic inequality which ultimately leave enormous gaps in health structures to be filled by the humanitarian sector.

As access to medical health care is a universal right, and although MSF does not have the intention or the measures to reach absolutely everyone, it does aim to be a medical aid organization without barriers. Obviously, this is a farfetched goal, yet it is not unachievable. Hence, when referring to the organization's principles of impartiality, neutrality and independence, MSF continuously work to identify and challenge barriers in order to ensure health accessibility for the most vulnerable. It does so through its organizational structures where members of the Association are able to influence the direction of MSF. Through this format, the motion on inclusion of people with disabilities was adopted, which in turn established dedication and

resources to identify relevant barriers, neglected patients, and inclusive frameworks. Thus, MSF need to identify the PWDs that do not access MSF services in order to identify barriers, and subsequently work on measures to overcome and ensure inclusion.

PWDs that do not access MSF services are affected by both temporary and permanent disability. By using the organizational structures and their patient-based approach, MSF was able to create institutional change in this regard. Moreover, six keys have been identified and adopted throughout the MSF movement to ensure inclusion. These areas of inclusive measures were challenged by the global pandemic of Covid-19 in 2019/2020. Barriers of attitudinal-, environmental-, and institutional characteristics have tested the emergency response to MSF – e.g. both through measures of communication and access to health. Although MSF is the world's largest medical emergency organization, it cannot reach everyone who are in need. The organization can, however, work restlessly to be a medical aid organization without barriers. A goal most ambitious, however not unachievable.

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