Conceptual Frameworks of Disability in the Occupied Palestinian Territory with a focus on the Palestinian legal and health systems

Literature Review - March 2021

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This literature review is part of the project ‘Disability Under the Siege’, a programme bringing together a community of researchers, educational practitioners, cultural institutions, advocacy organisations and disability led groups in the UK and Middle East. The project aims to contribute to research efforts by providing intellectual and logistical resources that local practitioners need to transform education provision for children with disabilities in conflict-affected countries. The Disability Under Siege Network+ Grant Ref: AH/T005440/1 is funded by the Global Challenges Research Fund (GCRF) and the Arts and Humanities Research Council.

The review was undertaken by Professor Rita Giacaman founder of the Institute of Community and Public Health (ICPH) part of Birzeit University. ICPH was established informally as Palestinian social action was emerging at the end of the 1970’s, then as a formal university unit, a department, and as an institute in 1998. Its mission and goals have been primarily defined by the extra-ordinary conditions of Israeli military occupation of the West Bank and Gaza Strip. The institute’s inception, growth and development were a response to the Palestinian community's need for generating the evidence required to develop independent and informed health policies, plans and programmes.

ICPH aims to contribute to the protection and improvement of the health of the Palestinian population through research, teaching the MPH and Diploma programs, and the capacity building of public health providers and planners. Its theoretical foundations are based on the notion that health is socially constructed; and on understanding health and disease in context, taking shape over the life course. Medical services are considered important for achieving health, but not sufficient, requiring additional action outside health services and within community and society to address the structural factors that influence health and well-being, such as economic, social, cultural, political, and environmental influences on health.

The Disability Under Siege Network+ Project is a co-created programme bringing together a community of researchers, educational practitioners, advocacy organisations and disability led groups in the UK and Middle East. It will contribute to research efforts by providing intellectual and logistical resources that local practitioners need to transform education provision for children with disabilities in conflict-affected countries.

For more information please visit: www.disabilityundersiege.org

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### Acronyms

<table>
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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>CHW</td>
<td>Community Health/Disability Workers</td>
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<td>CRPD</td>
<td>Convention of Rights of Persons with Disability</td>
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<td>DPOs</td>
<td>Disabled People’s Rights</td>
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<td>GMR</td>
<td>Great March of Return</td>
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<td>GUPD</td>
<td>General Union of the Palestinian PWDs</td>
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<td>HCRPD</td>
<td>Higher Council for the Rights of Persons with Disability(s)</td>
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<td>HWC</td>
<td>Health Work Committees</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability, and Health</td>
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<td>ICHR</td>
<td>The Independent Commission for Human Rights</td>
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<td>ICPH</td>
<td>Institute of Community and Public Health</td>
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<td>ICRPD</td>
<td>International Convention on the Rights of Persons with Disability</td>
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<td>MOE</td>
<td>Ministry of Education</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>MOSA</td>
<td>Ministry of Social Affairs ¹</td>
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<tr>
<td>MOSD</td>
<td>Ministry of Social Development</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<tr>
<td>OHCHR</td>
<td>Office of the United Nations High Commissioner for Human Rights</td>
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<td>oPt</td>
<td>Occupied Palestinian Territory</td>
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<td>PA</td>
<td>Palestinian Authority</td>
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<td>PCBS</td>
<td>Palestinian Central Bureau of Statistics</td>
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<td>PDC</td>
<td>Palestinian Disability Coalition</td>
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<td>PHC</td>
<td>Primary Health Care</td>
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<td>PWDs</td>
<td>Person(s) with Disability/ies</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<td>UNRWA</td>
<td>United Nations Relief and Works Agency</td>
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<td>US</td>
<td>United</td>
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<td>WG</td>
<td>Washington Group</td>
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<td>WHO</td>
<td>World Health Organization</td>
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1 The Ministry of Social Affairs was renamed as Ministry of Social Development by a presidential order on April 13th 2016. Therefore, we refer to it as MOSA whenever we discuss the 1999 law and MOSD when discussing the new 2019 draft law.
## 1 Executive Summary

The definition of disability has evolved over time away from the biomedical and charitable and perceived as inside the person, towards understanding disability as linked to the living environment, which can able or disable people, increase or decrease their capabilities, and equalize or not equalize opportunity. Various measures can be used to assess disability status among persons and societies, depending on the purpose of such assessments. In the occupied Palestinian territory (oPt) the Washington Group questions are used in censuses to estimate the number of Persons with Disabilities (PWDs) in the population which can be compared to other population groups, and where the census also identifies the cause of disability, which in the oPt (West Bank and Gaza Strip) also relates to various types of exposure to violence by the Israeli army and ongoing and chronic warlike conditions. The 2017 census results indicate that, using the narrow Washington Group definition of disability, there are over 90,000 PWDs in the West Bank and Gaza Strip, with at least 2500 reporting that their disability was due to direct Israeli army violence. Other measures should be used to estimate the degree of need for entitlements. Yet despite the rise of disability activism in the 1980’s, and the promulgation of the 1999 Disability Law which provides PWDs with access to a range of entitlements, various entitlements set by the Law were still not implemented at the time of writing this report. In 2019, this Law was updated to reflect changes in conceptions of disability, from the biomedical and charitable, to a rights based definition and understanding, with the new Draft Law still being debated in early 2021. Attempts to understand how disability is measured by the Palestinian Ministry of Health, crucial for the provision of entitlements, were met with failure. The lack of transparency, high centralization, excessive bureaucratization and control from the top and dysfunctionality, are all systemic problems affecting not only the health sector and our attempts to understand the workings of the system, but other sectors as well. The paper concludes by identifying some of the gaps requiring future research and interventions.

## 2 Introduction

This paper provides an overview of the differing conceptual frameworks used to define and measure disability, then places disability in the context of the ongoing warlike conditions in the occupied Palestinian territory. It contains a brief review of the history of the disability movement in the occupied Palestinian territory (oPt), and analyzes data from the Palestinian Central Bureau of Statistics 2017 data to identify the basic characteristics of persons with disabilities (PWDs) and factors associated with disability as compared to the general Palestinian population. The paper then focuses on the Palestinian legal framework which is key for obtaining entitlements, and compared the 1999 Disability Law with the draft Law of 2019, which is still being debated. It then includes a general description of the Palestinian ‘health system’, and the way in which various factors articulate to produce health system fragmentation and underdevelopment. Two key issues related to health services are then identified and elaborated on: the main services available to PWDs and access to health care problems; and developmental delay and early disability detection. It concludes by identifying key gaps for future research and interventions.
3 Objectives and Methodology

3.1 Objectives

1. Contextualizing the situation of PWDs in the oPt in the face of ongoing and protracted warlike conditions so that we can better understand the issues related to the legal framework and health ‘system’ and the limitations imposed by ongoing Israeli military rule, in relation to PWDs needs.

2. Analyzing the Palestinian Central Bureau of Statistics Census 2017 as variables relate to PWDs, and comparing basic characteristics of PWDs to the rest of the population.

3. Reviewing the legal framework, identifying the main gaps, and what is currently being done in reviewing the old 1999 Disability Law, and comparing it with the current 2019 Draft Law, including interviewing selected knowledgeable persons to help explain the comparison.

4. Reviewing the literature on health services to PWDs, and problems associated with access to health care and early detection of disability (which includes activities of the Ministry of Health and Ministry of Education), and conducting selected purposeful interviews with key persons to help explain some of the literature’s findings.

3.2 Methodology

Methods: a combination of methods were used:

1. Grey and international literature review

2. Data analysis of the Palestinian Central Bureau of Statistics 2017 Census as this related to PWDs

3. Content analysis of the 1999 Disability Law and the Draft 2019 Law

4. Selected interviews with knowledgeable persons in governmental and non-governmental organizations and PWDs who are active in the disability movement.

4 Findings

4.1 Disability in the context of the occupied Palestinian territory (oPt, West Bank, and the Gaza Strip)

Before we can discuss the legal framework and health ‘system’ or fragmented services related to PWDs in the oPt, it is necessary to highlight the differences among various conceptual frameworks used to define and measure disability in order to provide a foundation for how we understand then define disability; describe the context in which PWDs live in; and provide a short history of the disability movement in the oPt to bring us to the current situation.
4.1.1 A Conceptual Framework

Disability has been defined in various ways over time, with conflicting and contradictory concepts of disability\(^1,2\), and depending on the purpose of identifying. Historically, disability has been defined from a biomedical perspective, with a focus on disorders and diseases\(^3\). This medical/rehabilitation approach followed World War I when many were disabled for life with a limitation on functioning leading to the promulgation of laws guaranteeing certain rights like disability pensions, social services, rehabilitation benefits and work quotas\(^4\). Such benefits began to cover all PWDs in the 1970s in the United States (US). Yet the domination of the medical model continued whereby disability was seen as essentially a medical problem, with the experiences of PWDs examined and explained in medical terms, and where the push was to ‘normalize’ PWDs so that they can be integrated in society.

In the 1960s and 70s, a growing protest movement on behalf of PWDs in the US put forth the social model as a rejection of the medical model of understanding disability. The social model opposes the provision of governmental services based on the medical model. Instead, the root cause of disability is identified as social, not medical, inherent in society’s limitations of taking into consideration the requirements and needs of PWDs. In this framework, disability is seen as a result of injury or disease, and the physical, mental or emotional functional difficulties (or functional limitations) as resulting from impairment and restrictions on participation due to environments which do not support PWDs specific needs. The social model includes components related to the ability continuum:

\[
\text{Able} \quad \rightarrow \quad \text{Dis-able}
\]

and emphasizes environmental aspects creating the limitations coming from outside the person\(^5\). Various environmental factors can affect people’s functioning\(^5\) including people’s attitudes towards PWDs, availability of facilitating equipment, support services, working arrangements which are flexible enough to accommodate PWDs needs, public spaces and institutions which accommodate the needs of PWDs, transport, all of which are key factors in PWDs participation. In other words, the social model of the concept of disability is understood as multi-dimensional which includes impairments, activity limitations and participation restrictions\(^6\) related to PWDs in their living environment. It should be emphasized here that the relation between a specific health condition and functional outcomes is not linear, and can be affected by all sorts of environmental, personal and cultural factors\(^7\) both positively and negatively.

The human development model of disability rests on Amartya Sen’s functioning and capabilities approach, and adds the notions of equality, freedom and justice to the concept of disability\(^6\). The capability concept’s main focus is freedom, that is, the equality of freedoms among people is their capabilities to function in ways so as to have a good life, not only income and wealth\(^3\). The emphasis is not on GDP; the emphasis is on people’s lives instead of its usual links to poverty indicators. Here, disability is understood as a deprivation of functioning. This model addresses the limitations of existing models especially in resource poor settings, and their measurement whether with their focus on poverty or ability to buy commodities.
The capability approach emphasizes the type of life people are able to live, their practical opportunities, and achievement. Achievement is called functioning.

Evidence has demonstrated that disability is associated with low achievements, that is, lower education and employment rates and limited access to health services. In other words, PWDs experience multiple deprivations at the same time. Yet if disability is deprivation from functioning, then this can be due to interactions between resources, personal and structural factors (environment, the economy, laws, and institutions such as homes schools, work, and services) as well as policies, culture, and health deprivations to produce disability. This framework is an important framework for disability inclusion, especially for policies and practices, including in resource poor countries.

Overall, a definition of disability which is universally accepted does not exist, and no disability framework can include all the dimensions of disability, with different models having different theoretical perspectives providing particular views on disability in different contexts. Thus, the problem of varied disability measurements is the outcome of various conceptualizations of disability. Indeed, as a complex and multi-dimensional condition, disability requires a multidimensional approach, and different types of measures to be used for different purposes.

There are usually three purposes for identifying PWDs in groups: development of policies and services, monitoring functioning levels among populations, and assessing equalization of opportunities as the social model emphasizes. Given that improving capabilities is paramount, rehabilitation and prevention should equalize opportunities. This is the main purpose of the Washington Group (WG) questions which rely on the International Classification of Functioning and Disability as a guide. The WG questions are used in surveys or censuses, and provide data which can be compared across countries and groups. This is what the Palestinian Central Bureau of Statistics (PCBS) has used in its Disability Survey 2011 as well as the 2017 census.

The WG questions then are used for aggregate assessments and should not be used at the personal level, as for example, assessment of the degree of disability. Other measures which can identify personal level details, such as the disability experience, are also needed. Yet as with the WG, the social model also focuses on equalizing opportunities, and as such, cannot identify PWD needs for health or social or other services. In fact, even prevalence rates can be measured using different instruments for impairment, activity limitations, and also well-being. And this is why prevalence measures cannot be directly compared because different ways of estimations are used. However, for a grounded understanding of the situation of PWDs and the details of their lived experience, it is important to go beyond disability prevalence measures by examining the links between disability and functioning, and social agency in a particular context. And this requires the additions of particular variables to the available standard prevalence measures in line with different contexts. Besides, it is difficult to measure disability with accuracy in any case, which poses an additional problem in improving the capabilities of PWDs and equalizing opportunities.
4.2 The Palestinian Context

The continued and prolonged military occupation of the West Bank and Gaza Strip since 1967 has resulted in dispossession, displacement, land confiscation, the building of illegal Israel settlements on Palestinian land, imprisonment, siege, and generations of Palestinians exposed to long-term political violence by the Israeli army as well as Israeli illegal settlers on Palestinian land, and violations of human rights. With about 60% of West Bank land (Area C), controlled fully by Israel, and around 10% controlled by the Palestinian Authority (PA), and the remaining 30% controlled by both the Palestinian Authority and Israel, a key feature has been the continued expropriation and fragmentation of Palestinian land through various means, including bureaucratic and administrative control of land, water, resources, population and localities. Israeli army checkpoints have restricted mobility and access from one area to another, blocking the movement of people and goods, and destroying livelihoods(13).

The erection of the Separation Wall separating East Jerusalem and its surrounding villages from the rest of the West Bank compounded the problem of this access regime by reducing the West Bank into enclaves or social and economic islands cut off from each other with dramatic effects on the economy and society. It has also resulted in crowding Palestinians into several segregated political enclaves covering around 40% of the West Bank where 2 million Palestinians live. Thus, the development of all of the West Bank has been impeded. In addition, at the time of writing this review, the formal annexation by Israel of about 30% of Area C in the West Bank's bread basket, the Jordan Valley, seems to be imminent, with this annexation making life even more difficult than before, and leading to deteriorations in health and human rights in Area C as well as Areas A and B.

Palestinians in the Gaza Strip have also been under Israeli military rule since 1967. However the Gaza Strip has been subjected to a siege since the early 1990’s which intensified since 2007 with the breaking up of the PA and the divide between Fateh and Hamas, the two ruling authorities in the West Bank and Gaza Strip respectively. The siege of the Strip has resulted in the de-development and the destruction of the Strip’s economy by Israel(14). The conditions there are severe, with Gazans denied free access to the West Bank and abroad, including for much needed medical and other services. This isolation of the Strip by Israel is compounded...
by restrictions imposed by Egypt as well, and inflict severe hardships on the population there\(^{(15)}\). Adding insult to injury, and other than periodic attacks, Israel waged wars on the Strip in 2009, 2012 and 2014, with thousands dead, injured, displaced and maimed.

It has been argued that Israel uses maiming as a bio-political and deliberate tactic against occupied Palestinians. Termed as the 'right to maim', the practice of maiming is seen as an extension of 'the right to kill' in warfare and for self-defence which Israel uses as justifications for illegal and inhuman actions; that is, the right to disable\(^{(16)}\). Indeed, evidence indicates that since the beginning of the Great March of Return (GMR), a mass resistance and largely non-violent movement beginning in the Gaza Strip in March 2018, and interrupted since the outbreak of the COVID-19 pandemic, death and disability have proven to be heavy health, including mental health, burdens on civilian protestors and their families\(^{(17)}\). During this period 214 Palestinians including 46 children were killed, over 36100 including about 8800 children were injured. Of the limb injuries 156 resulted in amputations, with lives dramatically negatively affected\(^{(18)}\). Excluding the Gaza Strip GMR disabilities due to Israeli army violence, data analysis of the Palestinian Central Bureau of Statistics Census 2017 data set indicates that there are at least 2500 PWDs who reported that their disability was due to Israeli army violence, with 67% of those from the Gaza Strip compared to 33% on the West Bank.\(^{2}\) In other words, war and occupation are an important cause of disability, especially in the Gaza Strip.

### 4.3 A brief history and current status of PWDs in the oPt

The importance of the issue of disability exclusion and attention to the needs for the inclusion of PWDs began to take shape following the 1988 First Palestinian Uprising (\textit{Intifada}). Previous to this period, PWDs were largely invisible, and taken care of by charitable institutions sometimes together with orphans and the destitute. In the early 1980’s people with physical disabilities attempted to organize themselves because of: the lack of aids and prosthetics which could help them in being mobile so that they can be educated and employed; to spare other PWDs the suffering and difficulties they have gone through themselves; and because of the dissatisfaction with the then existing institutions serving PWDs\(^{(19)}\). However, a decade later, most of their recommendations and demands were still not implemented, until disability came to the forefront of political action against Israeli military rule. During the First Palestinian Uprising of 1988-1993, large numbers of mainly young adults and children were injured and disabled as a result of Israeli army violence, especially given instructions to break the arms and legs of protestors as a matter of policy, otherwise called the broken bones policy\(^{(20)}\). It is then that the concept of disability began to be transformed from a problem which brings stigma and shame to persons and families, to disability as a result of political heroism\(^{(21)}\). Various groups worked together, linked to what was called then the social action against Israeli military rule, leading to the establishment of the General Union of Disabled People (GUDP) in 1992. A community based rehabilitation program was established after training

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\(^{2}\) Obtained by statistically analyzing the PCBS Census 2017 data set.
community rehabilitation workers, and vigorous lobbying by all led to the promulgation of the first Disability Law by the Palestinian Legislative Council in 1999(23).

However, the actual implementation of the law was interrupted by the Second Palestinian Uprising of 2000-2004. In the meanwhile, the political factional splits affecting the country led to the gradual fragmentation of the GUDP and other civil society institutions working with PWDs. Thus, while GUDP still exists until today, some of its regional chapters operate as independent entities. A revival of activities took place in 2004 aiming to push for the implementation of the 1999 Disability Law. This is when the PA released a presidential decree(23), which called for the development of a Higher Council for the Affairs of Persons with Disabilities. The Council’s task was to oversee the implementation of the 1999 Disability Law by governmental and NGOs. This presidential decree was only adopted in 2012(24). Members of the Higher Council included governmental organizations, civil society organization, PWD organizations and the private sector. In May 2014, the PA became a signatory of the United Nations Convention of Rights of Persons with Disability (CRPD)(25).

In the meanwhile PWDs and some civil society supporters of the rights of PWDs regrouped again, and the Palestinian Disability Coalition was formed in 2017 in an effort to unify actions and lobby for change(26). This lobbying with the support of a UN agency working in the oPt led to the drafting of the Disability Law of 2019 which was submitted to the Presidential office on that year. Since then and up till end October 2020, the draft Disability Law was still being discussed and debated.

4.4 Palestinian Central Bureau of Statistics 2017 Census: initial analysis of the data set related to PWDs

Analysis of the 2017 Palestinian Central Bureau of Statistics (PCBS) data set revealed that 2.2% of the Palestinian population has disabilities in the West Bank and Gaza Strip (excluding East Jerusalem because of lack of PCBS access by Israel). This proportion does not include PWDs who are under five years old because the WG questions are not intended for use among very young children. This brings the total number of PWDs 5 years old + to around 90,000 persons, an under-estimate as information on children less than 5 years with disability is lacking, and also because the results will under-estimate the prevalence among 5-17 year old children, given child development and transition from infancy through adolescence limitations(11). What is interesting to note is the discrepancy between this number and the number usually cited by PWDs, the advocates of PWD rights and several international groups working in the area. First, PWDs and advocates for PWD rights use the wide definition WG of disability (5.8%), which include those who report some difficulty instead of only those reporting moderate and a lot of difficulty or not at all, bringing the total PWD group to around 240,000(27-29). They sometimes also cite the World Health Organizations’ (WHO) and other international group’s published proportion of PWDs worldwide, at 15% of the world population, although average life expectancies in different countries can increase or decrease this proportion considerably(30, 31); and even though WHO explains that of those, 2-4% experience important difficulties in functioning(32). It seems as if the disability movement locally is somehow influenced by what international groups use for numbers of PWDs in their advocacy strategies. It is understandable that lobby groups push in the direction of increasing
the proportion of PWDs in the population in general, as this could strengthen the case of PWD right. However, depending on context and purpose, this approach can be counter-productive in certain situations, for example, when it comes to the prioritization of actions, especially in resource poor environments. Currently, the costs of applying the 2019 Palestinian draft Law is being calculated, and it is already clear that the costs will be prohibitive, and require prioritization. There are also those who maintain that the PA will not promulgate the new Law because of the costs entailed. This calls for costing based on both the narrow and wide definitions to allow for the prioritization of implementation of the new draft Law over a period of time.

We now turn to a brief examination of disability by type using the narrow WG definition, and an initial comparison by age, sex, and selected demographic and socio-economic indicators. Using the PCBS Census 2017 data set which contains 20% of the population and is representative of the West Bank and Gaza Strip, we find that 1.2% reported a mobility disability, 0.7% seeing, 0.5% hearing and communicating each, and 0.4% remembering; and 1.6% had a single disability, while 0.6% had multiple disabilities. As one would expect, 17.5% of PWDs were 65 years old or more, 4.5% 50-64, 1.6% 19-49, 1.1% 15-18, and 1% 10-14 and 5-9 years old each. However, in contrast to the literature where more women are reported as with disability worldwide, 2.4% of Palestinian males were PWDs compared to 2% among females. These results require further investigation. There were more PWDs in the Gaza strip at 2.9% of the population compared to 1.8% among West Bankers. The difficult lives of people in the Strip (context above) may partially explain some of these results, likely compounded by disablement due to Israeli army violence, which affects men more than women. Regression analysis (to check for confounders and ensure that relationships between disability and associated factors are real and not confounded by other associated factors) revealed that overall, PWDs are on an unfair disadvantage compared to the rest of the population, and with males more likely to suffer from disability compared to females (I sometimes call this the paradoxical effect of patriarchy, with more men exposed to political and other forms of violence than women who tend to stay at home); with Gazans more likely to suffer from a disability compared to West Bankers; and with PWD families more likely to live in poverty (as indicated by the Standard of Living scale, and extended family arrangements, both proxies for poverty), compared to the rest of the population. Education and work were not included in the analysis because this requires separate analysis on children, then adults, then older people, which will hopefully be completed in the future.

4.5 The Palestinian Legal Framework

While the Disability Law of 1999 was certainly a move in the right direction, the problem was in its implementation as well as it essentially biomedical and charitable approach to disability. By 2019 there were calls for ‘updating’ or changing the law especially that the State of Palestine had signed the Convention on the Rights of Persons with Disabilities (CRPD) in 2014. There seems to be conflicting information regarding who began this process of updating the law and why. Some who work with the PA who were asked this question reported that the PA

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3 Information obtained by interviewing key persons from the Palestinian Disability Coalition
wanted to change the law after signing the CRPD, but lacked the needed funding for this process. A UN agency working locally stepped in and funded the production of the draft 2019 law which was prepared by Birzeit University’s Law Institute, and subjected to numerous discussions by different groups, with discussions ongoing. The UN agency is currently active along with others in estimating the costs needed to implement the new draft law. In contrast, at least two PWDs who we asked this question reported that the PA only began to work on updating the law and seeking funding when PWDs were writing a shadow report to the CRPD committee on whether the PA is adhering to the convention or not, as it was not.

Regardless of what prompted this initiative to update the 1999 Disability Law, it is clear that it needed updating (detailed report on the Law forthcoming). To begin with, the 1999 Law was written with a medical and charitable orientation without taking into consideration the role of the environment, broadly defined, in producing disability (so that the disability was understood as inside the person). It referred to PWDS as the ‘disabled’, which was offensive not only to PWDs but others who supported their call for equality. The responsibility for PWDs was relegated to the Ministry of Social Affairs (currently called the Ministry of Development and Social Affairs), again, reinforcing the charitable approach, especially that this ministry usually takes care of very poor people, the unemployed and the destitute.

The 1999 Law did not delve into women’s or children’s rights, an important element for the protection of women and children with disabilities. PWDs were exempted from custom taxes on medical, educational and transportation purposes, and included aspects such as: the right to access health, education and other services; the requirement of ensuring that at least 5% of the workforce at government offices and ministries would be PWDs; encouraging the private sector to employ PWDs through tax exemptions; integrating sign language in governmental offices and ministries; and ensuring the availability of the equipment and aids needed by PWDs to perform their tasks. However, the fly in the ointment was that the 1999 Law was not enforced in full and sometimes not even partially, or not at all. There were no mechanisms listed in the Law to ensure oversight, supervision, penalties and sanctions against institution or persons who did not abide by the Law. According to the results of our interviews with 18 key persons working with PWDs which included PWDs and a parent of a PWD, all participants reported that the 1999 Law was not fully implemented (report forthcoming). They explained that this was due to the costs entailed, or because decision makers did not prioritize PWDs; because of the lack of knowledge and awareness of how to deal with disability at the decision making level; the lack of public awareness and social support; or because Palestinian laws are not always compatible with each other, where some laws conflicted with the 1999 Disability law. Almost all reported that the 1999 Law did not specify responsibilities and competent authorities to ensure the application of the Law. Currently, the 2019 draft Law is still in discussion before being sent for promulgation, but the process was interrupted by the State of Emergency declared by the Palestinian President beginning March 2020 due to the COVID-19 pandemic.

4.6 The fragmented health ‘system’

Health care services in the oPt are provide by several sectors: the Ministry of Health (MOH), the United Nations Relief and Works Agency for Palestine Refugee in the Near East
(UNRWA) which caters to the needs of Palestinian refugees of the 1948 and 1967 Arab Israeli wars in the West Bank and Gaza Strip, Jordan, Syria and Lebanon, local and international non-governmental organizations (NGOs), and the private sector. However, international donors and organization have had a key role in funding disability access programs or as partners in implementation, and have been identified as key players\(^\text{(33)}\).

UNRWA provides health care and rehabilitation services to PWDs, and its disability program is implemented through Community Based Rehabilitation Centers. This includes the provision of rehabilitation services, assistive devices and home modifications, and supporting community and home based care\(^\text{(34)}\). However, it is maintained that UNRWA is not always able to cover the full costs of services to PWDs\(^\text{(33)}\). Almost all specialized rehabilitation services are provided by NGOs, estimated at 55 NGOs in the West Bank and 33 NGOs in the Gaza Strip, either at very low or no cost, and to a lesser extent by the private sector if PWDs can afford the cost\(^\text{(33)}\). A local NGO network has been operating a community based rehabilitation scheme having trained and continuing to train Community Based Rehabilitation Workers since the early 1990’s in both the West Bank and Gaza Strip covering over 240 localities\(^\text{(22)}\).

Although the Palestinian National Health Strategy of the MOH for 2014-2016 for example, affirms that policies will focus on provide comprehensive and affordable services, especially for vulnerable groups including PWDs, in fact the MOH is described as not having a holistic approach for health and rehabilitation services for PWDs, as is the case today\(^\text{(33)}\). It is emphasized that there are significant gaps in dealing with the needs of hearing, intellectual and severe disabilities; and insufficient availability of mobility and support devices important for social and economic independence. At the time of writing this part of the review (November 3-7, 2020), PWDs and their supporters were holding a sit in at the entrance of the Palestinian Legislative Council calling for free health care for PWDs, which was passed as Law in 2004, but not implemented in full\(^\text{(23)}\).

Various factors contribute to an impeded and stunted development of the health sector in both the West Bank and Gaza Strip. The PA is not in control of all areas of the West Bank, and this major impediment comes in the way of the provision of health services to all, including
to PWDs. Especially since the COVID-19 pandemic engulfed the country beginning March 5 2020, the MOH has been unable to reach Area C (over 60% of the West Bank), where many of the COVID-19 cases were initially diagnosed among Palestinian workers in Israel who move back and forth from Area C to Israel and back, without being checked for the virus infection by Israel. While some NGOs and NRWA do operate health services in Area C, especially mobile clinics, this remains constrained by Israel’s control with limited or no access to primary health care by the population living there, and also because of Israeli settler violence especially during the COVID-19 pandemic. In addition, the almost total reliance on external funding has enforced neo-liberal agendas believed to have made the economy less viable and more dependent on Israel. At the same time, given the vagaries of funding and frequent shifts in foci from one type of program to another has not allowed for systematic long-term programming to develop. Likewise, the chronic starvation for funds brought about largely by the constraints imposed by Israeli occupation on the economy and society, and allegations of PA corruption and cronyism, has meant that the pandemic was prioritized over basic health care services, including for PWDs. At the time of writing this report, the viral community spread had become entrenched, continues to rise exponentially on the West Bank, and is termed ‘uncontrollable’ by some officials.

The Gaza Strip was spared the COVID-19 spread until August of 2020. The Strip has been under a choking Israeli siege with very limited movement of people and good in and out of the area, and which has ironically spared Gazans the spread of the virus until August of 2020. In addition, the Gaza Authorities set up quarantine centers on the borders with Egypt, and tested all coming in, placing those with infection under a strict quarantine for two weeks before allowing them to enter the Strip. However, despite these measures by late August 2020, 12 community transmission cases were reported with immediate fears that an outbreak would be difficult to contain because the Strip is so densely populated; with inadequate housing and water supply and very limited access to electricity; and with an already highly strained health infrastructure and chronic shortages of medications, equipment, supplies and personnel. The number of cases in the Strip has also risen sharply since August. One must wonder about the effect of the pandemic on PWDs access to health and other services in both the West Bank and Gaza Strip, especially PWDs with mental disabilities. Although available information mainly warns against PWDs being most at risk, initial reports indicate that the COVID-19 pandemic has exacerbated the already existing marginalization and discrimination against PWDs in the oPt. However, it is crucial that systematic investigations are conducted on the effects of the pandemic on PWDs as soon as possible.

Literature and postings from international groups working in the area seem to be following guidelines developed elsewhere. For example, one international group emphasizes women with disabilities, children and the elderly without taking into consideration the fact that the proportion of Palestinian men who are PWDs is in fact significantly higher than among women, raising the question of why men are excluded, and how this problem can be addressed, given that world figures report the opposite pattern. Of course, women are more vulnerable because of patriarchy. However, in our context, it is men who are more exposed to political (and economic) violence, and have a higher proportion of disability, and also need attention, support and programmatic action. Another international group working in the area notes that
one of its programs on disability inclusion has a strong gender component with its focus on girls and women with disabilities when my understanding of gender includes men and women as WHO also explains. And this particular problematic understanding of gender is in fact common among international groups working in the area. It is as if Palestinian men are stigmatized a priori and considered the ultimate cause of violence against women, when of course Patriarchal relations are a factor, but there are also communal, national, economic, political and global factors which influence gender relations.

The grey literature on access to health care also emphasizes the problems faced by PWDs given the ongoing Israeli military rule. For example, WHO’s Commission of Inquiry recommended Israel to refrain from using lethal force again different groups in the population, including PWDs. Another international group highlights the fact that Palestinians are struggling to meet their basic needs, especially persons with disabilities who are often overlooked and are not represented in development and relief efforts, and because of the restrictions on movement by Israel which affect PWDs particularly badly, given these restrictions make it very difficult for PWDs to access the services they need (including health and rehabilitation).

At the national level, understanding the health sector alone vis a vis the needs and rights of PWDs is also problematic in that the responsibility for fulfilling the needs of PWDs is jointly coordinated among the MOSD, which is assigned the ultimate responsibility for PWDs, and the MOH and the Ministry of Education (MOE). In fact, sectoral data on disability is never collected and managed as it should be and as part of the national strategy/development plan for this sector. As we have also found with interviews, data is available sporadically so that it is not possible to build a picture allowing for the planning of interventions. The country in general suffers from dysfunctional political and institutional systems of authority, and from poor coordination between and within ministries, including the MOH. That is, inter and intra-sectoral collaboration processes are highly bureaucratic and centralized, and at times, with laws of various ministries contradicting each other so that the implementation of the law is hindered (forthcoming report on the legal aspects). Secondly, the split between the PA and Hamas complicates matters as what is legislated in the West Bank may or may not be applied in the Gaza Strip, and with coordination among the three ministries on the West Bank and in the Gaza Strip seriously curtailed. Yet despite these shortcomings, attempts to obtain basic information on PWD services and needs from ministries on the West Bank yielded limited, although important initial results related to two priority questions: how diagnoses are made to allow PWDs to receive entitlements; and what is being done in the area of early childhood development/developmental delay and the early detection of disability.

It must be stated here that the personnel working in ministries responsible for disability programs were as helpful as they could be and seemed to really care about the issue of disability and serving PWDs, but were constrained by either a lack of documentation, adequate oversight, or ‘orders from above’ not allowing them to provide answers to

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4 The sections on diagnosing disability and developmental delay/early detection of disability are based on interviews with selected persons working in ministries and with PWDs.
questions. That is, the problems are systemic, not personal. For example, I have tried via several interviews with key people from ministries and by contacting key PWDs who are active in the rights movement, to find answers to essential questions on the way in which PWDs obtain entitlements based on the MOH diagnoses, to no avail. An active PWD tried hard to help, and tried to gather different sources of information, and came back with no answers either, although the person had warned me that answers are not to be found. Yet, answering the questions is essential for assessing the process, and for PWD access to entitlements and included: who are the members of the diagnosis committee, what are their specialties, how are they chosen, did they have special training in identifying the different types of disabilities, do they have continuing education on the subject, how often do they meet, and are they supervised. I was ultimately referred to a high level MOH person who is responsible for following up the COVID-19 pandemic and who has no time for answering such questions. Even an international funding group technically and financially supporting the PA with its disability program revealed that indeed, they do not 'share or disclose information easily'. However, there was a response to the question of the basis upon which the MOH committee deems a PWD eligible for entitlements according to the 1999 Law. The answer was that the basis is an old Jordanian diagnostic criterion used till today, which is highly likely to need revision. This is also confirmed by a study completed in 2016, which reports that the disability classification and certification process controlled by the MOH is often conducted using outdated laws and processes(33).

It should be pointed out that, according to the 1999 Disability Law, PWDs are entitled to free health care (although expensive medications and laboratory tests are either lacking or insufficient) and various other benefits, including purchasing vehicles and equipment without tax, that is, if they satisfy the diagnostic criteria. However, it seems that this is erratically and only partially applied using outdated diagnostic guidelines. A World Bank report confirms these findings in general, which includes that the disability assessments are medical in nature, that the referral mechanisms are generally had hoc, and success outcomes are unknown; and the absence of no clear financing strategies and budget allocations to ensure PWD services sustainability(33).

The other key set of questions related to early childhood development/developmental delay and early disability detection, a fundamental aspect related to the prevention and/or amelioration of disability. Until recently, the MOH had the responsibility of taking care of children from birth till 2 years of age. During this period, the MOH would also provide vaccination for these children, and generally speaking mothers brought their children to primary health care (PHC) clinics on time because in the oPt mothers and families understand the importance of vaccination in protecting their children from disease. At the same time, the MOE’s and MOH’s school health programs also screens children beginning at age 6 years when they enter governmental schools. The children 2-6 years fell into the cracks and were not screened at all because once child vaccination was completed mother do not bring their children to PHC clinics, unless they were sick with fever, diarrhoea or vomiting and other such obvious and visible health problems.
Beginning 2018 a pilot program was initiated with the support of an international funder focusing on early childhood and early detection of disability for children 2-6 years old. The MOH, MOE, and the MOSD are all responsible for parts of this program, which is being piloted at the moment in two districts of the West Bank. It seems that Palestinian personnel from the MOH, MOE and MOSD were trained in Sarajevo for some reason (with the initiative of the international funder). Once back they used the Sarajevo diagnostic instrument for developmental delay and the early detection of disability without validation in the local setting, and began the pilot implementation, which continues up till today. While the MOH uses this instrument in PHC clinics, because women do not usually bring their children of that age to PHC unless they are sick, one knowledgeable interviewee agreed with what is known; that yes, the scheme does not cover all children, and needs further development whereby somehow, the PHC team could conduct home visits and regularly screen children 2-6 years old which can be easily identified based on clinic records. I stressed the importance of including community health/disability workers (CHW) into the PHC team and ministries’ organizational structure. Once trained such rehabilitation workers could visit homes ensure that all children are screened, and can assist mothers or caretakers in caring for children with disabilities, including realistic health education provision which women can apply given their circumstances. While CHW’s are currently involved in the pilot scheme, they are still not part of the organizational structure of ministries, and are employed only based on the availability of grants. This leads to fluctuating programs given the vagaries of funding noted for many research and intervention programs which shift focus from one group in the population to another periodically(47). What is ironic is that, ultimately, CHW employment costs are rather less than employing doctors and nurses to do the needed work. In situations when CHWs are well trained and supervised, they could do just as good a job as anyone else at the clinic in the initial screening and early detection of disability, and then referral to the clinic if needed, in addition to supporting carers at home. Unfortunately, and despite the fact that local non-governmental (NGOs) organizations have trained and employ CHWs successfully, the governmental system continues to lag behind even though the MOE had approved the CHW training operated by a local NGO, and accredited it as a two-year diploma program.

The early detection pilot also entails activities operated by the MOE. Previously, the MOE was responsible for primary and secondary schools, with pre-school, kindergarten, and nursery services supported entirely by NGOs or private sector. At the same time as when the pilot MOH program began, the MOE began to operate also as a pilot 100 pre-school centers. The MOE School Health Program personnel were trained along with the MOH and MOSD personnel in Sarajevo, and the MOE adopted the same developmental delay/ disability detection screening instrument. While this is a good beginning, this MOE program does not follow up NGO or private pre-school initiatives, leaving a large proportion of children without screening for the early detection of disability. Moreover, I was also told 5 that at least half of the children 2-6 years old do not attend any pre-school whatsoever. These results emphasize

5 Information obtained from interviews with key informants.
the need for CHWs at the primary health care level who can actively visit homes and do what is needed for the early detection and prevention of disability among children.

Overall, the PA seems to be moving in the right direction on the West Bank by focusing on screening for developmental delay and early detection of disability among a priority group, children. However, entrenched systemic problems come in the way of effective action, especially given the difficulty of coordinating activities among the different ministries involved, and likely inadequate training and supervision/oversight. This is compounded by the problem of the sudden international funding shifts which can and have in the past dishevelled PA programs, and the serious constraints on the PA’s budget and ability to reach the different parts of the country. In the meanwhile, PWDs are enduring triple captivity: they are captive under Israeli military rule, captive because of PA systemic and budgetary problems, and captive because of their disability. When it comes to women and girls, given the patriarchal nature of Palestinian society, women and girls with disability are in a quadruple captivity.

5 Discussion

This paper highlights the general context in which PWDs in the occupied Palestinian territory live, namely under a long protracted conflict and Israeli military rule, with the resulting stunting and underdevelopment of all systems, not only the legal and health ‘systems’. It brings out the issue of disability caused by wars and exposure to political violence, and not only biological predispositions or socio-economic and environmental factors which can produce disability. Disability due to war continues to be under-studied and requires more attention from researchers and policymakers alike. This is so especially that in the Palestinian context and elsewhere, political violence not only kills people, but produces disability, sometimes deliberately, as is the case with the oPt (the Right to Maim).

The oPt has a strong disability movement which has achieved much in the past, including the promulgation of the 1999 Disability law. However, this movement has had peaks and troughs, and was affected by the general internal political situation. The splits along factional lines have seeped into the disability movement whereby today, new groups are emerging claiming their dissociation with political factionalism. This is no different from what is happening in other institutions, for example, universities, student unions etc. At the time of writing this report, PWDs and their supporters were still staging a sit in at the Palestinian legislative Council since November 3 (almost 1.5 months!) and continuing, and demanding free health care for PWDs and their families, as the 1999 Disability Law stipulated, but never implemented in full. It is hoped that this protest will lead to positive results, and inform other PWD movements elsewhere in the region. The other insight obtained from this study is that of the influence of international groups pushing for rights oriented approaches, then failing to support the PA in the financial and effective implementation of such rights approaches, which are expensive, and prohibitive for low and middle income countries, let alone an authority under Israeli military rule.

The results indicate that, as expected, PWDs are on an unfair disadvantage compared to the rest of the population with PWD families more likely to live in poverty, and with Gazans more likely to suffer from disability compared to West Bankers. Interestingly there were more
females with disability compared to men among the Palestinian population, a result which contrasts with the global literature and warrants further investigation.

As we observe for other ‘systems’, the legal system related to PWDs in the oPt suffers shortcoming in terms incompatibility among different laws promulgated for different ministries and within ministries, lack of proper implementation, clear procedures, oversight, accountability, and transparency. While the draft Disability law of 2019 works to bring in the notion of rights into the 1999 disability law which was primarily based on a charitable and biomedical model, discussions of the new Law seem to be never ending, mainly because PWDs insist on their active involvement in all stages of its implementation, yet the Palestinian Authority wants the upper hand. Such power struggles are part and parcel of the various Palestinian ‘systems’, including health, education etc. The health sector in particular is currently overburdened with the COVID-19 pandemic, which is exposing many of its inadequacies, high centralization, excessive bureaucratization and control from the top, and dysfunctionality. Such systemic problems are complicated further by the lack of control of the PA over borders, land, water, crossing etc. and with the pandemic, the lack of social protection for all Palestinians in the oPt underlies the current PA crisis and its failed attempts at imposing lockdown with COVID-19 cases spiralling and hospitals operating at what we understand is full capacity.

### 5.1 Gaps for possible consideration

Further research is needed to understand the process of accessing health care services by PWDs and their families, including the basis upon which a person is defined as ‘disabled’. Specifically, it is important to know the composition of the Committee responsible for providing disability cards to people, who they are and their specialties, whether they assess only medically or also taking into consideration the broader social and environmental factors producing disability, how they were chosen, how long do they serve on the committee, if they had special training in identifying the different disabilities or not, including continuing education, on what basis such decisions are made, and whether they are effectively supervised or not. This type of research is aligned with the expressed needs of PWDs, especially clear since the PWD and supporters sit in at the Palestinian legislative Council began.

Another gap which warrants our attention is the issue of early detection/developmental delay. As it stands, a newly developed program targets children 2-6 years old, who fall into the cracks between the end of immunization at 2 years and school entry at 6 years. It is important to research who is doing what, on what basis, why, on what basis, the division of labor between the Ministry of Health and Education (both responsible for children 2-6 years old), and the extent of coverage of these children, in addition to training, continuing education, assessment, evaluation and oversight. Special emphasis should be placed on children who do not attend pre-school and kindergartens, who were estimated by one of our studies to be around 2/3 of the children in this age group.

A third gap inspired by this report is whether accurate and reliable data on disability due to war and conflict is available in Jordan and Lebanon. As I understand it, data is scattered in Lebanon, and not collected systematically. If this is the case, then it would be important to
research disability among war torn populations, for example, Syrian refugees in Lebanon and in Jordan, in addition to possibly other types of refugees.

A fourth gap directs us towards supporting PWDs and their supporters in training and capacity strengthening. While collecting information for this paper, several documents were sent to me, written by PWDs or local NGOs supporting the cause of the rights of PWDs. While such groups are actively engaged in consultation processes with their constituency, the problem is that their reports are suboptimal. Much can be done in the area of capacity strengthening in conducting focus group discussions and interviews. The documents written by such groups reveal a real need for training in developing questions (without putting words into people's mouths) relevant to the aims and objectives of the research, research design, interview and focus group discussion techniques, writing of results, analysis of results, and presentation of findings in systematic ways to allow for strong conclusion to emerge. This is why training in focus group discussion first, then qualitative interviews (to include sample selection and types of sampling) will help strengthen their work as scientific evidence which can be used for different purposes. Perhaps such training, if conducted in remote, could also include PWDs and their support groups in Jordan and in Lebanon, should there be a need.

A fifth gap pertains to PWDs and their support groups (largely local NGOs) learning how to write reports using available data. Numbers and percentages cannot be used without turning them to knowledge, and also comparing one group with another. While the oPt is lucky to have the PCBS producing periodic data, including specific surveys on disability, such data is rarely used properly and systematically. Although this is a more ambitious type of training, requiring particular initial skills, it is nevertheless important, and can help PWDs and their supporters in quantitative data analysis and report writing which can be used for advocacy not only with the PA, but also with international groups.
6 References


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Conceptual Frameworks of Disability in oPt
