LEAVING NO ONE BEHIND

Did the response to COVID-19 accommodate the needs of persons with disability? Perspectives from the Arab world
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Did the response to COVID-19 accommodate the needs of Persons with Disability?
Perspectives from the Arab world

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Abstract

The Sustainable Development Agenda introduced “Leaving no one behind” as a guiding direction for development policies and initiatives. With the release of “The Missing Billion”, report in July 2019, global, regional and national social development dialogues re-energized advocacy efforts to advance disability inclusion in development and humanitarian settings.

Unfortunately, COVID-19 has exposed deeply entrenched inequalities and prejudices that persons with disabilities have been facing, which have worsened because of the pandemic. This paper attempts to look at two specific aspects of discrimination against persons with disabilities -- namely statistical discrimination and health discrimination, both proxies for other types of discrimination. The analysis concludes by calling for a comprehensive society-wide, inclusive approach to development and for increasing investments to help identify and track vulnerabilities that inform preparedness and response measures to COVID-19 pandemic and beyond.

Introduction

Just before the eruption of the COVID-19 pandemic, the United Nations Secretary-General called on all member states and international and national social actors across all sectors of society to get ready for a decade of action\(^1\). With only ten years left to achieve the Sustainable Development Goals (SDGs), embracing the “leave no one behind” motto could not be timelier.

By the end of October 2020, and after almost a year into the global COVID-19 pandemic, the total number of confirmed cases has exceeded 40 million, and, significantly, more than one million deaths. The Arab region has recorded some two million cases, constituting around six percent of the global disease burden\(^2\).

While human history will mark the year 2020 as the year of the pandemic, COVID-19, has the designation “19” because the very first cases were reported in China in December 2019. The speed with which it spread across the world caused the World Health Organization (WHO) to declare it a Public Health Emergency of International Concern (PHEIC\(^3\)) on 30 January 2020\(^4\)\(^5\).

The pandemic not only uncovered social inequalities, it also widened and exacerbated them. most notably for a very fragile and vulnerable group of the population. Long marginalized and discriminated against, persons with disabilities found themselves facing their most difficult challenge ever and on all fronts as a result of the COVID-19 pandemic.

Of the world’s nearly eight billion people, the statistic show that 15.1% experience some form of disability\(^6\). WHO estimates that in the East Mediterranean region alone, there are more than 100 million persons with disabilities\(^7\), the near equivalent of the entire population of Egypt, the Arab region’s most populous country.

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2 https://covid19.who.int/
3 A PHEIC is an extraordinary event that poses a risk to the public health of more than one state because of the international spread of the disease, thereby potentially requiring a coordinated international response
5 https://www.who.int/publications/m/item/covid-19-public-health-emergency-of-international-concern-(pheic)-global-research-and-innovation-forum
6 https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/5f284cb69af8a9396df3f81c/1596476607957/v3_TheMissingBillion_revised_0620.pdf
In Syria alone, with its ongoing conflict of more than a decade, recent evidence suggests that one-in-four aged 12 and above has a disability\(^8\). It is not only in conflict-affected countries that disabilities are prevalent, but also in relatively stable, middle income Arab countries. At least one in four persons aged 65+ has a disability in Egypt, Jordan, Morocco and Oman\(^9\), more than half being women. This calls for a closer examination of the gender dynamics and the response of government authorities and local communities to COVID-19 in order to determine how it might have exacerbated the already existing inequalities experienced by the persons with disabilities.

During the pre-COVID-19 era, persons with disabilities were already marginalized in terms of accessing quality health and education services, including reproductive health information and services, and they were facing significant and systematic discrimination throughout the Arab states region, with very few exceptions in a few countries\(^{10}^{11}^{12}^{13}\).
Persons with Disabilities’ rights at the international development arena

Attention to the rights of persons with disabilities is not a new area of concern for international development actors. The need to address the issue was perceived and advocated for as a key development priority for decades. In 1994, the International Conference on Population & Development (ICPD) called on “states to address the sexual and reproductive health needs of persons with disabilities” and it demanded “the elimination of discrimination that undermines the reproductive rights of persons with disabilities.” This was further reiterated at the ICPD Nairobi summit in 2019.

These concerns were galvanized by the historic agreement on the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 that was ratified by 182 member states including all the Arab countries. Following the CRPD, a global monitoring committee was established at the UN Human Rights High Commissioner’s office to oversee monitoring of the CRPD implementation by member states. The international community and international development organizations realizing that persons with disabilities are at a much greater disadvantage because of COVID-19, saved no effort to advocate for and develop guidance notes and policy briefs/statements in support of persons with disabilities during the pandemic.

Addressing the different needs of persons with disabilities throughout the Arab region is a pressing priority. Awareness and commitment have gathered increasing momentum in the Arab States region over the past two years, thanks in part to the organization of the international conference on disability and development that was hosted in Doha, Qatar in 2019, and the global/regional We-Decide initiative led by the United Nations Population Fund (UNFPA). At the inter-governmental regional level, the League of Arab States - through the Council of Arab Ministers for Social Affairs - is continuously engaging in and advocating for the rights and development of persons with disabilities in the Arab region.

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16 https://www.nairobisummiticpd.org/content/icpd25-commitments
18 https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx
19 https://www.unfpa.org/resources/covid-19-and-persons-disabilities-key-messages
22 https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1
24 https://drive.google.com/file/d/1H68RveMbU1kEnNYh3u6PvhDEjoyG6/view
25 https://drive.google.com/file/d/1ETvbgrO4Q-DQy6a9YCyJ94z-DKsgLxb/view
26 https://www.dicdd.qa/
27 https://www.unfpa.org/we-decide
This paper is an attempt to build on the regional momentum created by the aforementioned events, and to raise the awareness of policy and decision makers to the needs of this severely disadvantaged population group i.e. persons with disabilities and its sub-groups. We will examine two types of discrimination that persons with disabilities face worldwide and in the Arab region -- statistical/data discrimination and health-related discrimination -- and how they relate to the added challenges imposed by the COVID-19 pandemic.

**Discrimination against Persons with Disabilities**

Different scholars and societies have defined discrimination in different manners. Persons with disabilities needs have neither been adequately addressed in mainstream social development policies nor in COVID-19 pandemic response plans. Despite global, regional and national level efforts to advance persons with disabilities’ rights, their needs were not sufficiently integrated.

Many Arab societies attempted to address persons with disabilities’ needs from a medical, philanthropic or protective perspective. The Arab region, however, still lacks a comprehensive development approach that identifies, acknowledges and builds on the strengths and qualities that persons with disabilities possess. In the following sections, the dimension of discrimination against persons with disabilities will be explored to determine whether it can be attributed – during the era of COVID-19 pandemic – to chance or choice.

**Statistical (data) discrimination**

Statisticians count what/who they know, and what/who governments and sponsors are interested in learning about. The term “statistical discrimination” is borrowed from economic discrimination theories. Originating in the 1970s, researchers theorized the tendency of decision makers to make decisions based on “statistical assumptions” that result in profound discrimination. In this analysis, the concept is fine-tuned to reflect on decision makers’ designing interventions and policies based on “statistics” and data that are inherently defective because of the inability to accurately define the main variable, i.e. disability. Consequently, the nature of the problem under study -- its size and the diversified needs of persons with disabilities -- remains invisible to planners and decision makers.

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29 [https://www.cdc.gov/eeo/faqs/discrimination.htm](https://www.cdc.gov/eeo/faqs/discrimination.htm)
30 [https://civilrights.findlaw.com/civil-rights-overview/what-is-discrimination.html](https://civilrights.findlaw.com/civil-rights-overview/what-is-discrimination.html)
Measuring disability is a contentious issue, one that has been the subject of conceptual and legal debates for years. First off, in order to measure something, there has to be agreement as to what it is and what it is not. This is where the data or statistical challenge begins, even though what all the Arab governments endorsed in the CRPD in 2006 is clearly defined. The various persons with disabilities-related Arab national policies and strategies employ different definitions that further complicate efforts to streamline disability data. Even the term “persons with disabilities” is not necessarily acceptable or agreed to by all within the region. Some of the terms used in Arab countries include persons with special needs, people of determination, disabled or impaired persons, and differently abled persons.

Lead agencies at national levels in the region are even more varied in their terminology and definitions of persons with disabilities making it almost impossible to coordinate and align their strategies in any coherent framework. These include national councils, ministries of labour, family, social affairs, health, and human rights committees etc.

All Arab countries are publicly committed to improving the welfare of persons with disabilities and enhancing an enabling environment to the extent that there has been considerable progress throughout the region. Yet, as the national statistical offices and the census/national surveys and leading departments and authorities persist in their use of diverse tools to collect data on disabilities, their different methodologies and definitions, and the different approaches/sets they employ in applying the Washington Group methodology, means the issue of synchronicity and the need for an agreed nomenclature remains unresolved.

Latest estimates of disabilities in the region range from 0.2% in Qatar to 5.1% in Morocco and up to 10.6% in Egypt (ESCWA 2018, CAPMAS 2017), far below WHO’s estimation of the global average at 15.1% (WHO 2020). Such wide variations from the global average can be partly attributed to measurement methodologies and definitions. In the absence of comprehensive national Civil Registration & Vital Statistics systems, that integrate a complete set of persons with disabilities data, governments in most Arab countries continue to rely on censuses and surveys when assessing disabilities. For example, the most recent surveys in Bahrain, Sudan and Syria that sought information about disabilities included just a simple yes/no question on having a disability. By way of contrast, similar surveys in Jordan, Morocco and Tunisia included a four-scale question in keeping with the recommendations of the Washington group.
It is not only that different questions and approaches are employed, but also the fact that in the Arab region they feature in the context of very different data collection exercises. Examples of these disparate practices and formats include workforce surveys (Egypt 2016), Demographic and Health Survey (KSA 2016), budget surveys (Yemen 2014, and Syria 2007), poverty survey (Iraq 2016) and censuses in a handful of Arab countries. Being “covered” in so broad a range and scale of assessment tools suggests a different conceptualization and focus on the part of the commissioning agencies and organizations, which implies that the contextual emphasis was not necessarily focused on persons with disabilities, their rights, and vulnerabilities.

Consequently, reported rates of disability in the Arab countries vary considerably and are prone to being significantly misreported. Much of the blame or responsibility for this can be traced back to the definition of disability adopted by the different authorities in the Arab region. The nomenclature is not standardized, data collection tools are not aligned and, when the questions asked are vague, as can happen, the responses translate into inaccurate estimations.

Arab region ministries of health (MOH) are all going through tough times as they respond to the COVID-19 pandemic in addition to their dealing with their regular share of challenges. Very limited data are available on the profiles of the affected populations, and almost none are broken down according to gender and age, let alone disability status.

WHO, as the global technical lead on the health response to the pandemic, keeps urging MOHs to provide timely and disaggregated data on the affected populations and vulnerable groups. It is well documented that COVID-19 is more aggressive in elderly population groups and even more aggressive where there are co-morbidities. Chronic hypertension, diabetes, heart disease, etc. are very likely to exist in most elderly people, not surprisingly the group registering the highest rates of disabilities in the region. Estimates show that in some countries, COVID-19-related deaths can reach 94% in the age group bracket of 60 years and above.

The vulnerable elderly are well documented as having the highest rates of disabilities in the region -- up to 20% in Yemen and over 30% in Morocco, according to the latest estimates [for the age group 65+].

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39 ESCWA – Disability in the Arab Region 2018
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Realizing the critical need for accurate data gathering, and in order to minimize discriminatory data-related practices, participants at the Global Disability Summit in 2018 identified and listed it as one of the Summit’s ten commitments to “Gather and use better data and evidence to understand and address the scale, and nature, of challenges faced by persons with disabilities, using tested tools including the Washington Group Disability Question Sets” 40.

UNFPA executive director, along with other leaders of international organizations, used the Summit to “call on the global community to strengthen quality and comparable data on disability...urging Member States to collect and disaggregate data on disability according to the criteria of the SDG indicator framework” 41 with a plea that doing so would ultimately contribute to making the invisible, visible 42.

The SDGs provide an opportunity, with the growing political commitment, to support greater inclusivity for persons with disabilities in terms of equitable and sustainable development. However, if this is to be achieved, better data on persons with disabilities is an essential requirement in both development and humanitarian settings. Strong political commitment must be accompanied by better tools and aligned processes. Governments and international organizations constitute a crucial part of the solution, but can also be part of the challenge. The diversity of key players involved in addressing/advocating for the needs and rights of persons with disabilities can lead to double and sometimes even conflicting and incompatible counts. Standardization of definitions and alignment of tools is a vital starting point to facilitate integrating data from various sources in order to arrive at a complete picture of persons with disabilities realities in the Arab region.

42 Data revolution that makes those who are often invisible, visible. UNFPA regional Director remarks at the Doha International Conference on Disability & Development 2019 (https://www.dicdd.qa/en/dynamic-pages/group/4)
Health Services discrimination during COVID-19

Humans are prone to taking health for granted until something goes wrong. That is not the case where persons with disabilities are concerned, since a significant part of their lives – if not all – is the opposite. Moreover, many persons with disabilities have additional underlying health needs that make them especially vulnerable to severe symptoms of COVID-19, should they contract it. Also, persons with disabilities may be at increased risk of contracting COVID-19 because information about the disease, including symptoms and prevention, are not provided in accessible formats such as print materials in Braille, sign language interpretation, easy-to-read captions, audio captions, and simplified high contrast graphics.

Health discrimination is of paramount importance because it can be a proxy for other components that reflect structural discrimination, as can be the case with education, transport and housing. With the widespread institutional closures including schools and universities, students with disabilities – no matter their age, grade or literacy level - lack access to information and education, to key resources including teachers and rehabilitation programmes; and to supportive equipment.

As public transport systems ground to a complete halt or reduced services because of COVID-19, persons with disabilities who were dependent were unable to travel, even for basic supplies or critical medical appointments and rehabilitation services.

A few months into the pandemic, led by WHO, several health-concerned international development agencies attempted to improve coordination and support for the social sector’s response to the crisis and to enhance governments to capacity to react swiftly. To do so, they created a platform for national stakeholders to share their response plans and the lessons learned as well as to facilitate access to potential donors. Regretfully, none of the Arab countries that submitted health response plans to the regional platform referred to any measures or arrangements that persons with disabilities might need or require.

As COVID-19 continues to have wide-reaching effects across the globe, it is vital to understand the unique impact the pandemic has had, often negative, on persons with disabilities. Because most persons with disabilities have pre-existing ailments and are very likely on long-term medications, their requirements for help with basic tasks, the difficulties they encounter securing needed medications and healthy food during the pandemic, all combine to place them at higher risk of infection by the virus and of developing more serious complications if infected 43 44 .

43 UN-OHCHR 2020 “COVID-19 and the rights of persons with disabilities”
44 COVID-19 crisis challenges for persons with disabilities. IPS Opinion – August 20, 2020
The challenges persons with disabilities face become more complex when the disability is one that requires a full-time companion. COVID-19 testing and treatment facilities are not persons with disabilities-friendly, not merely in terms of physical accessibility, but also for isolation, quarantine and treatment purposes. Persons with disabilities are at much higher risk during the pandemic because of the need for close contact with caregivers and companions, already irregular body functions, higher risk of complications because of their existing disability, and often an inability to receive mainstream treatment for fear of pharmaceutical interaction with routine medical regimens that are disability specific.

The spread of the COVID-19 pandemic exposed the fragility of health systems in the Arab region and beyond. At a time when the Arab region was coping with a record high in terms of the number of people in need of humanitarian assistance, the pandemic brought new health burdens with more than two million confirmed and reported infections throughout the region as of October 2020 45.

Structural discrimination is also evident in the conversion to digital and virtual platforms for education and health care provision where diverse needs of persons with disabilities such as sign language, tactile language, psycho-intellectual difficulties have been taken into consideration. The decision by education and health ministries to move to virtual care and education was commended as an innovative solution for general health and education needs. Going virtual, however, and not allowing for the health and education needs of the deaf-mute, blind, mentally and physically challenged and their dependency on such services was an egregious omission.

The situation becomes grimmer if the persons with disabilities is an elderly individual, facing the much higher mortality rates associated with COVID-1931, given that elderly persons with disabilities are disproportionately at risk because of the pandemic. Estimates show that, in the Arab region, more than 40% of those aged 60 years and above have some degree of disability and that the majority in this category are women 46 47.

45 https://www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports/
47 ESCWA - Disability in the Arab Region 2018
The higher disability rate among older women may not be solely due to their longer life expectancy. Gender dynamics may limit their access to information, healthcare and education more so than older men. Several developed and developing countries continue to report localized COVID-19 outbreaks in nursing homes where personal protective equipment is generally lacking at a time when health facilities struggle to not only protect their patients but also their staff and service providers.

Adding to the healthcare challenge faced by persons with disabilities as a result of the pandemic, is the fact that most, if not all, healthcare workers engaged in the COVID-19 response have not been trained to deal with persons with disabilities. In this regard, the education sector is a little more fortunate than the health sector because there are teachers who are specifically trained to deal with the different types of disabilities. There may not be enough of them, but at least they do exist, which, sadly, is not the case in the health sector.

It is therefore crucial for policy makers and planners to realize that accessibility to care consists of a lot more than installing a ramp for wheelchairs at a hospital or clinic entrance. True, there are specific criteria for a facility - clinic, classroom, school or office - to be classified as “physically” accessible. These include ramps with a handrail, specially designed doorways, toilet seats, washbasins, desks, light switches, emergency exits and door handles. Yet, meaningful accessibility to healthcare also and crucially includes the service provider, means of communication and health education materials and medicines.

Lack of inclusive, persons with disabilities-friendly transportation is another detrimental factor that significantly contributes to poor health, limiting opportunities for education and employment and consequently exacerbates financial and health poverty. The latest UN estimates show that around 70% of the Arab population live in cities, with urban populations around the world expected to reach seven billion by 2050 (UN-DESA 2018). It is also estimated that only 50% of the world population has access to convenient public transportation, that is, which is within 500-1000 metres. Even the latter statistic is irrelevant to persons with disabilities’ needs, all the more so in the Arab region. Under no circumstances would a 500 metres limit be convenient or suitable for the millions of persons with disabilities in the Arab region whether urban or rural residents, or those unfortunate persons with disabilities trying to flee from conflict or a natural disaster, or trapped in a refugee camp setting.

56 High level political forum: Ensuring that no one is left behind - Position paper by persons with disabilities, 2016
57 https://adgs.un.org/goals/goal11
Even in the few instances where public transportation is available and inclusive, schedules have been cut back as part of pandemic lockdown measures, leaving persons with disabilities unable to travel, missing critical medical appointments and often unable to meet their basic health and nutrition needs.

The Arab region has its share of specific issues and problems that have been compounded by the COVID-19 pandemic along with systemic fragility and ongoing conflicts. Sexual and reproductive health is yet another area where societal and health system discrimination dehumanizes persons with disabilities’ SRH needs in normal times, much less in a time of crisis such as during the pandemic. With MOHs throughout the Arab region re-purposing their health facilities and service providers, and supply chains to provide the COVID-19 response, the unmet and unfulfilled SRH needs of the persons with disabilities become further aggravated.

As COVID-19 continues to have a wide-ranging impact across the globe, it is crucial to note how persons with disabilities are uniquely affected by the pandemic in terms of health, education, and transport. Barriers to full social inclusion of persons with disabilities include inaccessible physical environments and transportation, the unavailability of appropriate and relevant information, health supplies and technologies, non-adapted means of communication, gaps in service delivery, and discriminatory prejudice and stigma in society.

60 https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/13921/IDS_Disability_Briefing_Final.pdf
61 Sexual and reproductive health services for women with disability: A qualitative study with service providers in the Philippines – BMC Women's Health 2015
Responding to the Pandemic

Persons with disabilities are well recognized as a vulnerable part of society. Despite the resilience and determination of persons with disabilities to cope and move on, the pandemic has brought with it additional challenges considering such needs as maintaining social distancing, hand hygiene, avoiding undue contact with surfaces, wearing face masks etc. Service disruptions in all sectors of the society have further compounded this fragility.

All the countries in the Arab region have initiated their own nationwide responses to COVID-19, mostly with some guidance and support from international health and development partners. Several months into the pandemic, a number of Arab countries have conducted multi-sectorial assessments for their national response plans that have been focused primarily on strengthening the health systems and prioritizing health system capacity upgrades to accommodate the potential rise of infections. However, despite nationwide measures to mitigate against the health systems’ collapse, very little attention has been paid to marginalized groups including persons with disabilities.

These response plans have attempted to incorporate multi-sectoral coordination components, looking mainly at health, education and the economy to try and limit the socio-economic impact of the pandemic and the expected associated rise in poverty.

Some reports highlight the fact that most national response plans assumed a blanket response and did not devote specific attention to the level of risk imposed on different population groups. Although most of the Arab countries implemented sporadic activities that target persons with disabilities including, for example, financial and mental support and educational materials, a comprehensive response that identifies and addresses the needs of persons with disabilities remains missing.

63 https://rb.gy/cyofgl
Leaving No one Behind

Conclusion

COVID-19 has provided the whole world with a needed opportunity not just to advocate but more especially to directly address several of the accessibility problems that persons with disabilities face. Going virtual is a case in point since it helps immediately overcome physical barriers and, in some instances, the need for physical companions to help with certain types of disability. It requires investment from the outset to enhance the digital skills and infrastructure, but it offers high potential and a long-term positive social return on investment. Yet, going virtual has its limitations since, inevitably, there are persons with disabilities subgroups that cannot and do not have access to the required technology.

The CRPD requests all Member States to “take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters”67.

The CRPD provides the legal backing, and the SDGs and the ICPD provide the political commitment for states to improve the situation of persons with disabilities during times of emergency and in development contexts. Addressing the rights and needs of persons with disabilities requires a comprehensive multi-stakeholder and multi-sectoral approach. Therefore, different stakeholders are called upon to join hands and take account of recommendations that include:

- Donors and international organizations need to:
  - Invest heavily in inclusive programming for development and humanitarian assistance. Donors should leverage their powers, require that all relevant initiatives are disability-inclusive, and require disabilities and gender disaggregated and standardized data.
  - Strengthen partnerships with domestic and international Civil Society Organizations to develop comprehensive approaches where persons with disabilities are included in all development and humanitarian programmes and initiatives, from conceptualization until execution.

- Members of parliament and policy/lawmakers need to be sensitized, trained and engaged in analyzing/reviewing discriminatory policies/laws and empowered/equipped to advocate for and propose non-discriminatory laws aiming to realize a disability inclusive policymaking process. National budget line items need to be looked at through an equity and disability-lens to ensure narrowing the inequity gaps between the different population groups.

- Ministries of planning and service ministries should ensure that all COVID-19 related information and services including virtual consultations, testing/isolation facilities, media campaigns, supplies and all services are fully accessible and inclusive. The state should ensure the continuity of services provided to persons with disabilities before the pandemic and prevent any discriminatory practices. Service providers should be continuously sensitized to the rights and needs of persons with disabilities across the full healthcare continuum. Special attention needs to be given to persons with disabilities who are intellectually and mentally challenged and, as a consequence, not likely to be able to communicate their needs/sufferings.

- Academia has an important role to play: aside from training medical and nursing students, law students, and teachers, there is a need to invest heavily in schools of architecture and urban/civil planning in order to produce generations of planners and designers who will build an inclusive future.

A whole-society approach is needed where INCLUSION is the key word. Inclusion in healthcare, education, social policies, statistics, media, urban planning and in all dimensions of life, persons with disabilities rights are indispensable for achieving the SDGs and a world where “no one is left behind”.