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Disability Rights in the Middle East: Opportunities and Obstacles

CHRISTINE SARGENT

Across the Middle East, two key dynamics characterize contemporary disability rights movements: dynamism and fragility. Disability activism, new communication platforms, legislative interventions, and capacity-building reflect palpable currents of change and innovation—which are often driven by ground-up initiatives increasingly led by disabled persons’ organizations (DPOs). At the same time, the COVID-19 pandemic and protracted crises stemming from war, displacement, underdevelopment, and climate change pose threats to health and well-being across the region, with especially grave implications for disabled persons and their movements.

**Disability
and Equality**

Fourth in a series

Two dilemmas present themselves when writing about disability rights in the Middle East, and both involve defining terms. First are the tensions inherent in the category “Middle East” itself, which favors particular (neo)colonial cartographies while diminishing local projects of regional identity and placemaking. Depending on the organizational body one consults for inclusion and exclusion criteria, different versions of the Middle East emerge. One must also consider the profound economic disparities that shape life across a region encompassing some of the highest- and lowest-ranking nation-states on the 2020 Human Development Index.

Here, I follow the United Nations Economic and Social Commission for Western Asia (ESCWA) roster, which includes Algeria, Bahrain, Egypt, Iraq,

Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates, and Yemen. ESCWA’s Inclusive Social Development Section has generated two major reports on disability in the Middle East, in 2014 and 2018. These reports offer unparalleled data aggregation for developing a regional perspective.

The economic inequality and political heterogeneity that characterize ESCWA members directly pertains to the second definitional issue at stake: disability. The preamble to the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes that disability is “an evolving concept.” (Adopted by UN headquarters in 2006, the CRPD opened for signatures in 2007. As of 2021, 182 countries have signed and ratified it; 9 remain signatories only, while 7 have taken no action.) Article 1 of the Convention offers the following definition: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

By embracing this definition, the CRPD created an authoritative global standard that affirms the fundamentally *social* nature of disability. The social model, as enshrined in the convention, represents decades of efforts by disabled activists and allies to unsettle individualistic models that situate disability in terms of individual tragedy or medical defect. Scholars and activists continue debating and revising the social model, seeking to better account for the complexities of embodied experience, to recognize disability’s intersectionality, and to challenge neoliberal and neocolonial co-optations of human rights discourses.

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These concerns inform a current paradigm shift from disability rights to disability justice, which seeks to emphasize how intersecting oppressions inform ableist social structures and logics. The framework of disability rights, however, is currently dominant in the Middle East. (These distinct but overlapping frameworks remind us that theorizing and organizing reflect specific historical, economic, and cultural contexts.) Both approaches share an insistence on the social and political foundations of disability.

As of September 2021, all ESCWA members have signed and/or ratified the CRPD. Iraq, Kuwait, Mauritania, Palestine, and Sudan have ratified or acceded to the convention without signing, whereas Lebanon has signed but not ratified. ESCWA states also vary in their adoption of the Optional Protocol, which establishes communication and inquiry procedures for violations.

The CRPD calls on member states to recognize the societal, environmental, and institutional barriers that disable. It obligates them to enact legislation that promotes the human rights of persons with disabilities and prohibits discrimination based on disability. ESCWA states have responded unevenly to this mandate.

Jordan's Law No. 31 of 2007 on the Rights of Persons with Disabilities, for example, has already gone through a substantive overhaul since its initial passage shortly after the government signed and ratified the convention. Law No. 20 of 2017 was a response to demands by DPOs and civil society organizations for a revision more fully aligned with the terminology and spirit of the CRPD, to provide clearer mechanisms for integrating disability rights into and across existing legislation. But some countries have failed to update existing laws—since the 1980s in Libya's case, or since the early 2000s in Lebanon's.

Both older and more recent laws often rely on antiquated paradigms and terms. Oman's Sultanate Decree No. 63 of 2008 positions disabled persons as recipients of care rather than subjects with rights, and emphasizes rehabilitation. While rehabilitation can be an important tool for preserving quality of life, its centrality to the law risks an overly medicalized focus.

Palestine's Law No. 4 of 1999 defines a person with a disability as: "Any individual suffering from a permanent partial or total disability, whether

congenital or not, in their senses or in their physical, psychological, or mental capabilities to the extent that it restricts the fulfilment of their normal living requirements in a manner not usually faced by those without disabilities." This definition conveys a still-typical positioning of disability as located in the individual (in contrast to the CRPD's interactive and environmental emphasis).

There is a selection bias to my examples in this essay, which focus on Jordan, Iraq, and Lebanon. The economic and demographic profiles of the Gulf states render them somewhat unique, generating material and social conditions that depart significantly from their more populous and geopolitically vulnerable neighbors to the west. The relatively less urbanized North African states also face a different set of constraints and challenges than the smaller, densely urban states in the Levant. My own selective focus in no way implies a lack of important developments in either of these two subregions.

To capture the complexities of both the region and disability, we need to look across interconnected scales of social life. This means tracking between methods and sites, from transnational and global organizing to the development of state-level policy and civic activism, as well as the politics of care and constructions of personhood that inform everyday experiences of disability.

SHIFTING NARRATIVES

Disability is part of the shared human experience, but it is shaped by specific material and social conditions. Across the Middle East, shifts are taking place in local disability narratives—the collective and quotidian ways that people make sense of and respond to embodied impairments. These changes reflect ongoing efforts by rights activists, expanding and deepening the role of disability rights in everyday life.

As ESCWA's 2018 "Report on Disability in the Arab Region" makes clear, data collection and accuracy remain major challenges. All reporting states documented notably low rates of prevalence that range from below 1 percent to just above 5 percent of the population. (The World Health Organization's 2011 "World Report on Disability" placed the average disability prevalence rate

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between law and reality
emerge in education.*

among adult populations at 15 percent, with a wider range of 11.8–18 percent between higher and lower income countries.)

Only three ESCWA members have fully implemented the Washington Group on Disability Statistics' Short Set (WGSS) of questions in their most recent national-level surveys. The Washington Group is one of the UN Statistical Commission's consultative "city groups." Its protocol aims to standardize and improve global disability data by focusing questions on degrees of capacity across six functional domains: vision, hearing, mobility, cognition, self-care, and communication.

Even among states using the protocol, estimates of prevalence can vary, because the Washington Group recommends that calculations include only those respondents who answer questions about capacity and functioning with "a lot of difficulty" or "cannot do [it] at all." But Jordan typically cites its national rate of disability as 11.4 percent of the population, including those who respond to WGSS questions with "some difficulty." If the WGSS recommendation is applied, the rate drops to an astonishingly low 2.7 percent of the population. Morocco and Yemen have similar patterns.

The use of screening questions, especially those including the word "disability," is still common in governmental and nongovernmental surveys across the region, creating a twofold problem. First, even the CRPD's standardized definition of disability inevitably relies on sociolinguistic categories to map the culturally constructed contours of bodies, minds, and persons. Interpretive differences pertain less to translational accuracy than to the fact that the labels of "physical, mental, intellectual or sensory" delineated in the CRPD possess their own philosophical, religious, medical, and popular genealogies. The WGSS questions offer one potentially effective way to recognize and accommodate the instability and specificity of the term "disability."

The second issue that makes screening questions problematic is stigma. Popular, academic, and organizational reports on disability in the Middle East often refer to a shared set of terms when describing attitudes, practices, and beliefs (often glossed as "culture") regarding disabled persons. These include shame, embarrassment, fear, and hiding.

In my own ethnographic research, I found that Jordanians frequently situated disability stigma in a teleological narrative of development and progress. In other words, there was remarkable consensus around the "past" having been worse and the present offering unparalleled opportunities and progress. But research by historians of disability in the Middle East like Sara Scalenghe and Kristina Richardson suggests more dynamic and flexible experiences of bodymind impairment and societal responses in the past. Additionally, social scientists like Benedicte Ingstad (who draws on work with community-based rehabilitation projects in Botswana) have argued that accusations of hiding people with disabilities can obfuscate and distort complex realities of caregiving, especially under conditions of material deprivation and hardship.

Nevertheless, concerns about family members restraining and hiding disabled persons from their wider social networks are documented in diverse sources and across the region. Such practices are often framed as vestiges of traditional mindsets.

Jordan's most recent shadow report on the implementation of the CRPD, submitted in 2017 by a coalition of DPOs and the King Hussein Foundation's Information and Research Center, documented multiple instances of disabled persons, especially those with intellectual or developmental disabilities, being chained and abused by family members or abandoned at residential institutions for unacceptable lengths of time—in some cases, for decades. These practices continue on a global scale, as shown in a 2020 Human Rights Watch report, "Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide." Ultimately, confinement and restriction—whether stemming from logics of punishment or protection, or the sometimes blurred boundaries between them—are clear human rights violations.

Despite the persistence of such practices, disability representation, especially through popular and social media platforms, has played a transformative role in shifting narratives and norms. In Jordan, the state-run JTV channel airs the program *Yowm Jadid*, which frequently invites disabled persons and family member advocates to share their experiences and raise awareness about disability issues in Jordanian society. On the privately owned Roya channel, the program *Dunya ya Dunya*

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features both informational and entertainment-focused segments centering the experiences of disabled persons and their families.

More recently, the virtual platform Habaybna.net, founded in 2017 by Reem and Mohammad Al Faranji, has worked to address the lack of up-to-date, reliable Arabic-language resources on childhood intellectual and developmental disability. The Faranjis relocated to Jordan after the winter 2008 Israeli bombardment of Gaza, when one of their sons, who was already experiencing language delays, stopped speaking entirely. Habaybna maintains a robust Facebook presence and provides links to an extensive YouTube channel, an article library, and an “ask an expert” direct phone line.

In Lebanon, the more controversial hidden-camera program *Al Sadma*, which first aired during Ramadan in 2016, featured several episodes designed to generate dialogue about ableism and disability stigma. As a program explicitly oriented around shock value, it raises questions about the ethics of enactment and simulation, yet the decision to call out normalized, public expressions of ableism is noteworthy. In a more academic vein, the open-access, bilingual English-Arabic journal *Kohl: A Journal for Body and Gender Research*, based in Beirut and Paris, published a special issue titled “Resisting Ableism, Queering Desirability” in the fall of 2020. What connects these otherwise distinct examples of cultural production is their desire to center disability and its attendant politics in everyday realms of experience and representation.

ENVIRONMENTS OF EXCLUSION

Accessibility is a multidimensional concept that encompasses more than built environments, but the state of infrastructure in much of the heavily urbanized Middle East does have an impact on disabled persons. Whereas rural areas are noted for their isolation and inaccessibility, unaffordable transportation and inaccessible buildings in Middle Eastern cities impede many disabled persons’ ability to participate in society. A 2020 report by the World Health Organization’s Eastern Mediterranean Regional Office on health-related Sustainable Development Goals lists only five ESCWA states where the percentage of urban residents falls under 70 percent (Egypt, Morocco, Somalia, Sudan, and Yemen).

In countries like Jordan, the lack of reliable and safe public transportation creates barriers for women, cited as one reason for their lagging

participation in the formal labor market. These issues are compounded for disabled women, who face heightened family resistance to their taking public transportation in general, as well as practical matters of accessibility and maneuverability. As a result, disabled persons—and especially women—must either rely on family members to help them exercise their right to mobility, or have the money to pay for taxis and drivers.

Amman’s Bus Rapid Transit project, now in its initial implementation phase after over a decade of delays, is an exciting development for the capital’s 4 million inhabitants (who represent 40 percent of the country’s total population). Although it faces hurdles in gaining public trust, the rollout offers reason for cautious optimism. The president of the Higher Council for the Rights of Persons with Disabilities, Prince Mired Raad Zeid Al-Hussein, has closely followed the project to ensure that the Greater Amman Municipality and its implementing partners remain committed to principles of inclusive design.

Accessibility cannot be reduced to material conditions. Across much of the Middle East, inclusive education remains both a rallying point and a source of major tension for policymakers, activists, and families. Some of the most glaring gaps between law and reality, between disability rights discourse and practice, emerge in relation to education. Inaccessible buildings and bathrooms pose challenges in and of themselves, but many of the barriers confronting disabled children might be framed more accurately as resulting from hostile institutions.

Administrators, parents of nondisabled students, and teachers can all create (and compound) the obstacles that continue to bar disabled children from exercising their right to education. The slow gains in inclusive education encapsulate the performative aspect of the post-CRPD disability landscape: documents, plans, and promises outstrip investments in practical and sustainable cultural, financial, and environmental adaptations. Angry and disillusioned families and students insist that politicians and analysts take more seriously the gaps between “ink on paper” and reality.

Although Jordan has extremely high rates of primary and secondary school enrollment, 79 percent of persons with disabilities do not receive any form of education. An estimated 10 percent of school-aged children are disabled, but statistics cited in the country’s most recent 10-year Strategy for Inclusive Education (2019–29) indicate

that only 1.9 percent of students with disabilities currently receive schooling services from either the Ministry of Education or the Ministry of Social Development.

Inclusion in Jordan still comes at a cost. Families are often asked by school administrations to pay additional fees to accommodate their child's disability, or they are tasked with finding (and compensating) their own shadow teachers. While these practices are technically illegal, change has proved difficult to enforce. But the situation in Jordan is by no means unique, and the country is arguably much better positioned than many of its neighbors to implement substantive reform over the next decade, given the level of government commitment.

CONVERGING CRISES

Ongoing and emergent humanitarian crises continue to threaten well-being and security across the Middle East, with particularly dire consequences for disabled persons and for disability rights movements and organizations. Humanitarian crises not only pose serious and disproportionate dangers for disabled persons, they also create immediate and long-term disabling conditions.

Contributors to the DPO-led assessment “Disability Inclusion Among Refugees in the Middle East and North Africa” dedicated their work to Yemeni lead author Sam Al-Ghauri, who was killed in Sana'a shortly after the report's publication in 2016. This tribute speaks to the intersections of vulnerability and insecurity. Coordinated by the Arab Forum for the Rights of Persons with Disabilities (AFRPD), the project sought to measure the gaps between the Guidance on Disability Inclusion issued by the UN High Commissioner for Refugees (UNHCR) and its actual implementation in humanitarian settings. Assessing local responses in Libya, Egypt, Yemen, Jordan, and Turkey, DPO teams identified the isolation of disabled refugees and displaced persons as a major obstacle to delivering humanitarian assistance and outreach.

Most refugees live outside camps—often in cities, but in conditions of high financial and social precarity. They are disproportionately affected by inaccessible urban infrastructures. The intersections between gender and disability, as well as the implications presented by different kinds of disability, render women refugees especially vulnerable to exclusion from services and outreach, while they simultaneously suffer from heightened psychological distress and risk of abuse.

The current situation in Iraq illustrates how prolonged and blurred boundaries between humanitarian emergency and everyday suffering create conditions of disablement, undermining disabled persons and DPOs fighting for political and social inclusion. In the past four decades, Iraqis have lived through the Iran–Iraq war, the Gulf War, the US invasion and occupation, and the rise and spread of Islamic State (also known by its Arabic acronym, Daesh). The widespread presence of explosive remnants of war and landmine contamination, decades of sanctions, and massive internal displacement have inflicted material and psychic trauma on the country's social fabric and infrastructure.

According to the International Organization for Migration (IOM), over 1 million Iraqis are still internally displaced, down from the more than 6 million displaced during the height of operations against Daesh (2014–17). Recent data from the UNHCR show that Iraq also hosts approximately 250,000 Syrian refugees, half of whom live in the northern city of Erbil. Official statistics on disability among these populations fluctuate wildly, but both local and international experts assume that Iraq's prevalence rates are significantly higher than the global average. In their 2019 report to the UN Committee on the CRPD, Iraqi representatives described Iraq as home to one of the largest populations of disabled persons in the world.

The Iraqi Alliance of Disability Organizations has been researching, advocating, and organizing since the earliest days of the US invasion. The English-language version of their website says, “We participated in the first demonstration on 12/4/2003 in front of the headquarters of the International Coalition Forces, in order to know the fate of more than 3 million disabled in Iraq.”

In 2020, the Alliance advised IOM's Iraq mission on its disability inclusion strategy, vetting a list of over 50 DPOs. Although the COVID-19 pandemic disrupted a plan to visit and conduct fieldwork with DPOs across the country, the IOM team was able to conduct phone interviews with 81 DPO representatives located in Iraq's 18 governorates. These interviews provided key data for IOM Iraq's 2021 report “Persons with Disabilities and Their Representative Organizations in Iraq.”

The gender imbalance among respondents in this survey (73 percent men) and the total absence of intellectually disabled persons reflect two recurring themes: disabled women and intellectually disabled persons face compounding barriers to

representation and inclusion. Notably, the report also excludes internally displaced persons and refugees due to a lack of identifiable DPOs in these communities. This point reinforces the AFRPD's finding that disabled persons in humanitarian situations often remain isolated from existing organizations and support networks.

In Lebanon, decades of disabled activism and community-building have long been undermined by the lack of a coherent state-level response. This dynamic has been worsened by the dire circumstances in Lebanon at present.

The Lebanese Physical Handicapped Union (LPHU), founded in 1981 and active during the entirety of the 1975–90 civil war, is a regional stalwart and model for nonsectarian and gender-inclusive advocacy. The landmark 1997 Oxfam publication *Gender and Disability: Women's Experiences in the Middle East*, edited by Lebanese activist Lina Abou-Habib, set an early precedent for intersectional, emancipatory research with disabled women and men.

But recurring political fragility, corruption, and lack of governance have created daunting barriers despite vibrant grassroots efforts by activists and families. Lebanon's current catastrophic collapse has been described by the World Bank as possibly one of the world's three most severe economic crises since the mid-nineteenth century. This meltdown has inevitably affected all facets of life. Food prices have risen astronomically (over 500 percent), half the population has been pushed below the national poverty line, and a 2020 World Food Program survey suggests that over 40 percent of families are facing difficulties with access to food and other basic needs.

The lira has lost 90 percent of its purchasing power, disproportionately affecting the working and poorer classes, who are typically paid exclusively in local currency. But a widespread banking crisis has extended this currency crunch to the middle and upper classes as well. Of particular concern for disabled persons has been the consequent buckling of Lebanon's medical and pharmaceutical industries, especially with the onset of COVID-19.

The concurrent traumas of the pandemic and the Beirut port explosion on August 4, 2020, underscore the harrowing conditions in which disabled Lebanese find themselves. Resulting in over 250 deaths and thousands of injuries, the explosion was a disabling event. In an August

2021 essay for *The Public Source*, LPHU president Sylvanna Lakkis, who has led the organization since 2001, said the group's field visits found that at least 800 to 1,000 people were disabled in the explosion and its aftermath. Yet no official figures have been provided.

Lebanon's Law 196, passed in the aftermath of the blast, registered all disabled survivors for social security coverage while also affirming their coverage by Law 220 on the Rights of Persons with Disabilities (enacted in 2000). But as *The Public Source* staff writers Karim Merhej, Kareem Chehayeb, and Christina Cavalcanti explain in the August 2021 piece, neither of these gestures has furthered the pursuit of justice. Law 220 relies on an outdated, medicalized framework that does not recognize many survivors as disabled, and its many aspirational commitments to disability rights (such as the right to education) have not been fulfilled in the absence of functional implementation mechanisms.

Meanwhile, Law 196 registered disabled survivors with the almost-bankrupt National Social Security Fund, whereas Law 220 grants full and free health insurance to disabled persons through the Ministry of Health. This contradiction has led both agencies to deny accountability. Each argues that the other is responsible.

This kind of situation is not unique to Lebanon. Attempts to mainstream principles of disability access and inclusion into existing policies and procedures require collaboration across ministries and agencies, which often creates stumbling blocks. But these organizational and structural challenges have proved especially immobilizing given the Lebanese government's current state of disarray.

AXES OF SOLIDARITY

The dynamic developments that characterize disability rights movements across the Middle East reflect both established histories of collaboration and emergent axes of solidarity. The past two decades have seen a number of notable regional initiatives to promote both intergovernmental and civil society cooperation on disability issues.

Preceding the CRPD, an ESCWA-sponsored conference, "Disability Conditions in the Arab World," held in Beirut in October 2002, resulted in 2003–12 being declared the "Arab Decade of

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Disabled Persons.” The conference identified ten disability issues for ESCWA states to prioritize, laying the groundwork for policy and legislative changes that would be given further impetus by the passage of the CRPD.

The Arab Forum for the Rights of Persons with Disabilities, based in Lebanon, comprises national organizations and associations in 12 countries and serves as a regional representative to Disabled Peoples International. The Arab Organization for Persons with Disabilities, based in Cairo, represents another regional network of DPOs and has hosted several major conferences on disability in Arab states since the signing of the CRPD. Several North African states also belong to pan-African disability networks.

The Qatar Foundation for Social Work launched the “Doha Declaration” as the culmination of the 2019 Doha International Conference on Disability and Development. The influence of wealthy Gulf nations in regional disability politics remains unclear, as certain cultural and political divergences have emerged (such as the United Arab Emirates’ decision to begin using the term “people of determination” in lieu of “people with disabilities”). Nevertheless, the Doha Declaration reflects Gulf states’ increasing interest in contributing more to regional programs and conversations.

In their more on-the-ground capacities, international organizations like Humanity and Inclusion

(formerly Handicap International), Inclusion International, the Special Olympics, and robust transnational university partnerships and projects are also active in the region. They promote—while sometimes coming into tension with—grassroots family- and DPO-led projects and plans.

The current moment highlights the fragility and contingency of these developments. The immediately life-threatening aspects of COVID-19, the debilitating effects of “long COVID,” and the pandemic’s still-unfolding impacts on governance, civil liberties, and economic stability have created global conditions of uncertainty. These conditions are amplified by humanitarian emergencies occurring in various parts of the Middle East.

From Lebanon’s dismantlement through corruption and mismanagement, to inescapable aerial assaults on Gaza and steady dispossession in the West Bank, to devastating hunger and malnutrition in Yemen, such emergencies imperil disabled communities and generate traumatic forms of mass disablement at the same time. Given these obstacles, global partners—especially those implicated in the region’s current instability through imperialist foreign policies and colonial legacies—should support and sustain Middle Eastern movements for disability rights and the work that their defenders do under increasingly trying circumstances. ■