



HEALTH RIGHTS IN THE ARAB WORLD FROM THE PERSPECTIVE OF DISABILITY INCLUSION

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INTRODUCTION

The right to health for citizens in general, and persons with disabilities in particular (being the subject of this paper), closely relates to the right to life and the right to an adequate standard of living, ensuring citizens enjoy the basics of a dignified life. In addition to the correlations between the right to health and all other remaining rights, the right to health is one of the main entry points into the different fields of life.

Furthermore, and before tackling the subject of health rights in Arab States from a disability inclusion perspective, it is necessary to briefly refer to a set of variables that affect this right, as well as other rights, for persons with disabilities, and other groups, on a policy, programmatic, and service level. The first variable relates to the various instances of colonization that many Arab States have been subjected to at different times, in the varied forms of occupation, which brought on wars, conflicts, the domination of resources, and destruction of key sectors, including the health sector; or in the dependence of many of these States on external donor funding, which influences priority-setting and intervention design on

different levels. This necessitates examining the extent to which these health-related interventions include components and requirements that are related to disability inclusion. The second variable is that most national policies, strategies, and interventions emanate from an individual approach to disability (i.e., the care/charity-based and medical approach),¹ widely evident, whether in sector-regulating policies, including the health sector, or in practice. The third variable is a set of questions regarding the maturity level of the state as a concept and in practice, in many regimes, including the Arab systems. This naturally reflects on the relationship between the ruling systems and their citizens and what the relationship entails in terms of roles and responsibilities, including the ruling systems' role in responding to the health rights and needs of citizens, including those with disabilities. Regardless of the fact that this variable applies to the majority of citizens, similarly to the other variables, it must be reminded that persons with disabilities, like others among the least-represented groups, often pay the higher price for the declining role of the ruling systems and the distortion of concepts relating to civic service.

The fourth variable is the vulnerable, disintegrated, and fragmented state of social protection systems or the like in numerous Arab States, leading to inquiries regarding the nature of these systems, if found, and how universal they are, and whether they are compliant with health rights, inclusive of persons with disabilities, and responsive to the requirements of the least-represented groups.

Many of the aforementioned variables deeply affect health sectors in Arab States on a policy and programmatic level. However, this paper is strictly concerned with presenting the most prominent aspects of the health sector in certain Arab States as an example. Specifically, it looks at the aspects which most impact the experience of persons with disabilities in enjoying their health rights with fairness, dignity, and independence. It is worth noting that the preparation of this paper adopted a rights-based approach to disability, established and promoted by the United Nations Convention on the Rights of Persons with Disabilities, systematically relying on literature review, observation, and a number of interviews with representatives of the Arab Forum for the Rights of Persons with Disabilities in certain Arab States.

We probably ought to briefly elucidate what we mean by an individual approach and a rights-based approach to disability, as they are essential to understanding disability as an experience on the one hand, and dealing with it on all levels on another. The individual approach (in general) is based on the concept that disability is an experience in terms of causes and effects. A matter that is exclusive to individuals with restricted sensory, mobility, intellectual/learning, and psychological functional capacities, whereby – according to this model – those different characteristics or restrictions result in hindering persons' participation in and execution of daily life tasks, without taking into account any other external variable or factor. This concept translates into policies, programs, and interventions (if found) that solely focus on rehabilitation and relief/care services, as well as establishing special institutions.

In contrast, the rights-based approach is based on the fact that the rights of persons with disabilities are exactly all human rights ones. They are universal, integral, and indivisible, in addition to their interdependence. Thus, disability as an experience is shaped through the existence of a set of individual characteristics (sensory, mobility, intellectual/ learning, and psychological difficulties) which are combined with a set of architectural, environmental, societal, and institutional obstacles and barriers, away from an acceptance of diversity, response to individual differences, and inclusion. This results in a negative interaction that prevents persons with disabilities from or restricts their enjoyment of rights and participation in society to the same extent as other citizens. This requires policy, programmatic and societal interventions, which not only target persons with disabilities, but also seek to fight discrimination, achieve justice and equality by overcoming the aforementioned obstacles and barriers, and incorporate disability inclusion requirements in all public policies, national and sectoral strategies, programs, and services.

THE FOUNDATIONS OF UNDERSTANDING AND ANALYZING THE RIGHT TO HEALTH OF PERSONS WITH DISABILITIES

There is a set of principles and pillars upon which we base our understanding, monitoring, and analysis of the rights of persons with disabilities, in theory and in practice. We shall go over these pillars in the following paragraphs succinctly.

If we are to define disability from a rights-based approach, we start by asserting that it is an evolved concept and an experience that emanates from the negative interaction between persons with disabilities and the environmental, policy, institutional, societal, and informational barriers, in a way that hinders or prevents their effective participation in society and their enjoyment of their rights with fairness, dignity, and independence. One of the most significant factors that could result in a paradigm shift in the reality of persons with disabilities with regards to their rights and their living conditions is the States' adoption of this concept on a legislative, judicial, and administrative level.² It is worth noting that most Arab States, such as Palestine, Lebanon, Tunisia, Yemen, and others, still apply the medical approach towards disability, the one that determines participation, the enjoyment of rights, and the ability to perform daily activities according to a person's individual sensory, mobility, intellectual/learning, and psychological differences. In other words, laws pertaining to persons with disabilities in these countries adopt a definition which focuses on the difficulty itself (i.e., the disability, whether mobility, sensory, intellectual/learning, or psychological), considering this difficulty as the factor that hinders the person's ability to perform daily functions like their peers, while neglecting the environmental, institutional, societal, and other barriers and obstacles, which greatly influence the disability experience. A few Arab States, such as Morocco, Jordan, and Egypt, have adopted more of a rights-based and social approach to disability, without taking the measures that may, in practice, affect policies, strategies, programs, and services, including those that regulate and form the health sector. The absence of this concept could lead to real crises on the levels of policies, roles, attitudes, authorities, and other.

For instance, ministries of health have a common belief that their role ends once the type and the severity of the disability is determined (regardless of any questions regarding the extent to which this service complies to quality standards). Moreover, ministries of health in most Arab countries often neglect responsibility for any disability-related programs and services, such as early detection, empowerment, rehabilitation, reconstructive plastic surgeries, and others, namely the interventions which when absent could affect persons with disabilities and threaten their right to an independent and dignified life.

As is the case in most countries around the world, the diagnosis of the type and the severity of the disability determines the set of rights and benefits that a person with disabilities is entitled to have. Many other variables that could deeply impact the formation of the disability experience are disregarded, such as the aforementioned set of barriers, in addition to the socio-economic reality surrounding the disability, gender, and other. Also, the adoption of a charity/medical approach in dealing with persons with disabilities, their rights, and their interests has resulted in the ministry of social affairs or ministry of social development (as it is called in certain countries) taking over the management of all affairs related to persons with disabilities in most Arab States. As such, persons with disabilities are simply considered as social cases. Consequently, other official institutions fail to honor their commitments towards persons with disabilities and their rights.

In the same context, accessibility, universal design standards, and the provision of reasonable accommodations, are examples of a set of principles and conditions that should be regarded as the foundations and pillars upon which all other rights are based, including the right to health. Therefore, the State and its institutions are obligated to include them in the design and implementation processes of health policies, programs, interventions, and other, considering the role they play in ensuring that persons with disabilities enjoy these rights. Many reports refer to the limited availability of access requirements for persons with disabilities to the health sector, whether in terms of the built environment (architectural structures), information, or services. In addition, medical staff lack effective communication means to deal with persons with disabilities, further preventing them from enjoying their health rights. Not to mention that they receive these services under inadequate conditions.

Furthermore, non-discrimination, equality, full and effective participation, transparency, and equal opportunity for remediation and grievance processes are some of the most important conditions for governance in public institutions, including health sector institutions. Persons with disabilities are subject to many violations. These are put forth by reports monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities and other international conventions issued by organizations concerned with persons with disabilities,³ as well as other international and national organizations. Often times, these violations result from the predominant negative stereotypes and attitudes that strip

citizens of their humanity and rights if they happen to have a disability. This is evident in many circles of society, even among health workers. These violations occur in conditions that are devoid of monitoring and accountability mechanisms, especially that complaint systems, if existent, lack the necessary components for persons with disabilities to be able to use them independently, fairly, and effectively, and benefit from them. Moreover, disability-based discrimination, including exclusion, neglect, rejection, and deprivation of possible reasonable accommodations, has not been legally prohibited, prompting accountability in numerous Arab States. This jeopardizes the ability of persons with disabilities to receive health services in a way that guarantees their right to self-determination and the respect of their dignity. It also questions the nature, quality, and the provision methods of these health services to persons with disabilities.

Lastly, persons with disabilities have the right to affordable, if not free, health services (as do their compatriots) especially if we take into consideration the close link between disability and poverty and the vulnerability of social protection systems and the (lack of) inclusion of persons with disabilities in the labor market, not to mention the limited opportunities for inclusive education. We should also remember that persons with disabilities, like other people, may catch a number of diseases that have no relation with their disability. Therefore, health systems must provide them with comprehensive health services with fairness and equality. However self-evident this fact may seem, some may find the rationale for its inclusion outrageous, noting that the latest World Health Organization (WHO) Global Report on Health Equity for Persons with Disabilities has mentioned it.⁴ The fact remains that the health sector in many Arab States lacks most requirements that enable persons with disabilities to receive all services with dignity and independently. This is evidenced by the limited measures – or lack thereof – to ensure the access of persons with disabilities to preventive services and treatment during COVID-19. A study conducted by the Arab Forum for the Rights of Persons with Disabilities that is yet to be published on social protection systems and their inclusion of disability focuses on this reality, using this specific period of time as a sample in Lebanon, Tunisia, Morocco, and Yemen. All of this to say that the predominant approach perceives disability as a variable that is separate from all other variables and circumstances.

POLICIES AND LEGISLATION ON THE RIGHT TO HEALTH FROM A DISABILITY INCLUSION PERSPECTIVE AND HIGHLIGHTING CERTAIN PRACTICES

The policies on health rights for persons with disabilities in many Arab States are in reality a set of characteristics and representations that we shall try to summarize in this part of the article.

First, our readings of the current policies and legislation on health rights for persons with disabilities show that, regardless of their premise and content, they have a common denominator. They are almost completely detached from the policies and approaches used to design and enact the country's public budgets. And as allocated budgets for any given item, sector, or societal category are a conclusive indicator of the State's level of care towards that item, sector, or category, we can deduce at least two things: first, the health sector is not a key priority for many Arab States; and second, the policies and legislations on health rights for persons with disabilities are mostly symbolic, and do not exceed the acknowledgement of these rights.

Second, disability is a quasi-absent variable in the design and adoption of public policies, including health policies. It seems as if it rarely crosses the minds of legislators and public policy makers, which leads to its systematic exclusion from the drafting process and content of these policies. If we look at the Palestinian law on public health for instance, we find that it does not include any mention or provision taking into account the need to take legislative measures in response to disability. The general direction seems to be the design of a separate law regulating the rights of persons with disabilities alone in order for them to be taken into account, without paying the necessary attention to ensure that this law is in harmony with other laws. In other words, despite the Palestinian Disability Law No. 4 of 1999 stipulating a number of health rights, Public Health Law No. 20 of 2004 does not include any text linking it to the former. Division and exclusion on a policy level increase with the constrictive pressure many Arab regimes exert on civil society. This results in limited opportunities for persons with

disabilities to fully, effectively, and truly participate in public policy making, including health-related policies.

Third, the adoption of the UN Convention on the Rights of Persons with Disabilities by many Arab States cannot be ignored, prompting the amendment of many laws regulating the rights of persons with disabilities, as was the case in Egypt and Jordan, in compliance with the Convention. Adhering to this Convention, and others, is an effective instrument used by persons with disabilities to advocate for their rights. It is a tool to exert pressure on the one side, and a reference to regulate the content of public policies to ensure this content is more in line with the rights-based approach on the other.

For example, after a 63-day open sit-in inside the Palestinian Legislative Council, demonstrators succeeded in pressuring the Council of Ministers into adopting a government health insurance system for persons with disabilities and their families, largely based on the Convention on the Rights of Persons with Disabilities. However, the States' commitment to applying these laws and regulations remains a concern, especially amid the limited indicators that could reflect the extent or lack of this commitment. To this day, the system's administrative measures, which are the catalyst for the system's implementation, have not been implemented. Moreover, the state of both the enjoyment of rights and service provision has not changed since the adoption of the health insurance system, except for its gratuitous aspect (free of charge services) and other minor entitlements.⁵

Fourth, certain States, regardless of their adoption of the medical approach in their policies, affirm that they have decisions and instructions issued by the ministry of health and ministry of social affairs aiming to implement the law regulating the rights of persons with disabilities, as is the case in Tunisia. However, many challenges and issues hinder their implementation, namely the ability of persons with disabilities to cover the required costs, especially under the ineffective person-with-disability card system. We add to this the many forms of discrimination and mistreatment persons with disabilities face when seeking health services or filling in relevant paperwork, and the hospitals' non-compliance with criteria related to building access and other application specifications.⁶

⁵The Palestinian Disability Coalition, 2023. "Parallel report to the United Nations Convention on the Rights of Persons with Disabilities in Response to the Official Report of Palestine."

⁶ Universal Periodic Review on the Rights of Persons with Disabilities in Lebanon, 2020 Report.

Lastly, considering the stance on drafting an endless list of recommendations, we shall simply highlight the following:

- The need to take the necessary measures to allow the full, effective, and real participation of persons with disabilities in the process of public policy-making, especially those relating to health rights, as the subject of this paper, whether the politicians consider it relevant to persons with disabilities or not, as no public policy is irrelevant to persons with disabilities, considering they are part of the social fabric of any country.
- There is also a pressing need for civil servants to reconsider the way they deal and perceive citizens with disabilities, for a disability does not lessen the value of a human being or a citizen. Rights cannot be divided, fragmented, and monopolized based on individual differences. Having inclusive, fair, and non-discriminatory health rights is one of the most important steps towards building a progressive State, as is the case for education rights.

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The Arab Forum for the Rights of Persons with Disabilities is a grassroots regional organization of persons with disabilities. It is comprised of 12 Arab States represented by organizations for persons with disabilities and the coalition of these organizations. The Forum aims to contribute to the protection and promotion of the rights of persons with disabilities in accordance with the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals, by building capacities, conducting studies, national, regional, and international advocacy, and influencing national policies and practices, allowing persons with disabilities the opportunity to participate in decision-making processes.