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**ORGANIZATIONS OF PERSONS WITH DISABILITIES
IN THE ARAB REGION
A PRELIMINARY STUDY**



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The study is part of efforts by the Economic and Social Commission for Western Asia (ESCWA) to promote disability-inclusive social development in the Arab region. It follows on a series of projects, including *Disability in the Arab Region: An Overview*. For more information, see <http://www.escwa.un.org/divisions/main.asp?division=sdd>.

Feedback from readers is appreciated. Comments and suggestions may be sent to sps-escwa@un.org.

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I. INTRODUCTION

Organizations of persons with disabilities play a key role in promoting their participation in decision-making, as called for in the Convention on the Rights of Persons with Disabilities, and thereby building inclusive societies.

In the Arab region, ratification of the Convention by 16 ESCWA member States has led to major reform in national institutions, laws and policies, which has been backed by organizations of persons with disabilities (also known as DPOs, or disabled people's organizations) and reflected in efforts to advance their rights, including in terms of education, political participation and social protection.

There is little information on DPOs in the Arab region. Research conducted by ESCWA in 2014 and 2015 has been used in this study, in which DPOs are defined as civil society organizations in which the majority of the board and members are persons with disabilities and whose primary objective is to promote their empowerment and inclusion. The definition includes organizations of family members or caregivers. Organizations that are not in either of those categories but work to advance the rights of persons with disabilities are classed as disability-specific non-governmental organizations (NGOs).

II. THE GLOBAL MOVEMENT OF ORGANIZATIONS OF PERSONS WITH DISABILITIES

Historically, disability was defined solely on the basis of an individual's impairment(s) and viewed from a medical standpoint. Responses focused on prevention, treatment and management of impairments, and persons with disabilities were considered objects of charity or care.

However, a social approach emerged in the latter half of the twentieth century, whereby disability was seen as a result of environmental barriers that, in combination with a person's impairment(s), hindered participation in society. Interventions shifted from the individual to the collective level, and societies and Governments came to be seen as responsible for identifying and removing physical, social, attitudinal and cultural barriers.

This shift in approach from the medical to the social provided fertile ground in which the global DPO movement could take root. Individual DPOs had hitherto been active in a handful of countries, but now a growing collective consciousness began to transcend borders:

The recognition by the State of issues for people with disabilities and their carers, and the provision of resources, played some part in the development of political consciousness by individuals with disabilities. [...] We saw the development of a social movement [...] informed by our common experience of systemic oppression. This moved beyond the disease labels of the biomedical model which was, and still is, the dominant defining aspect of difference and disability. We were discovering the social nature of disability, claiming a social definition which informs action [...] This was a fundamental element in the rise of a social movement of oppressed people speaking for themselves.¹

DPOs began to play a growing role in national and global forums, previously dominated by organizations for persons with disabilities (disability-specific NGOs), and thereby helped to deepen understanding of disability and cement the realization that persons with disabilities have the right and are best placed to inform policymakers of their needs and aspirations.

¹ Newell, 1999, p. 47.

A defining moment for DPOs came with their involvement in the end-stage negotiations on the Convention on the Rights of Persons with Disabilities. Drafting of the Convention was “the first such process to so extensively facilitate the participation of civil society, and it was noted by numerous government delegations during the General Assembly’s adoption of [the Convention] that the participation of disabled persons was critical to ensuring delegates’ understanding of the issues at stake”.² The slogan “Nothing about us without us” that emerged at the time has become a watchword for the global disability movement. The Convention was adopted in 2006 and is the main source of guidance on disability policy for its 160 States parties.³

Under the Convention, States have an obligation to involve DPOs in decision-making (article 4) and monitoring of the Convention’s implementation (article 33). The Convention also sets forth how DPOs can work with the Committee on the Rights of Persons with Disabilities, the body of experts mandated to monitor implementation of the Convention by the States parties. DPOs can: make written submissions on country-specific information; request briefings with the Committee; deliver oral statements during Committee sessions; work with the Committee during country visits; and intervene in procedures concerning communications, such as training and the representation of alleged victims.⁴

TABLE 1. THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
ON THEIR REPRESENTATIVE ORGANIZATIONS

<p>Article 4: (3) In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, <i>through their representative organizations.</i></p>
<p>Article 29: States parties [...] shall undertake to: [...] (b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including: [...] (ii) <i>Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.</i></p>
<p>Article 32: (1) States parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, <i>in particular organizations of persons with disabilities.</i></p>
<p>Article 33: (3) Civil society, <i>in particular persons with disabilities and their representative organizations,</i> shall be involved and participate fully in the monitoring process.</p>

Note: Author’s notes are in italics.

III. ORGANIZATIONS IN THE ARAB REGION

Changes in the approach to disability around the world and the growing commitment of Governments to the rights of persons with disabilities have been echoed in Arab countries. In 2004, the League of Arab States declared the Arab Decade for Persons with Disabilities, the first set of principles and objectives in the

² Guernsey, Nicoli and Ninio, 2007, p. 4.

³ For the latest information on the ratification of the Convention and its optional protocol, as well as declarations and reservations, see <https://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&lang=en>.

⁴ See Annex II of the Convention on the Rights of Persons with Disabilities in CRPD/C/11/2.

region for promoting the inclusion of persons with disabilities. In addition to the 16 ESCWA member States that have ratified the Convention, 7 have ratified its optional protocol. This section aims to review broad regional trends and identify gaps in knowledge and research.

A. STRUCTURE OF THE ARAB DPO MOVEMENT

DPOs are well established in some countries but in their infancy in others. The DPO movement in Lebanon, for example, is longstanding and has evolved in the context of a diverse civil society, and many DPOs have been set up in Jordan, some with Government backing.⁵ Research by ESCWA, however, shows that DPO movements are in the early stage of development in several Gulf Cooperation Council countries.

Potential factors behind the growth of the DPO movement in Egypt have been closer ties with the global movement and the involvement of national DPOs in drafting the Convention. Judging by the number of DPOs established since the Convention was adopted, the same could be said of other countries such as Mauritania and Morocco. Political and social changes, such as the 2011 uprising in Tunisia (box 1), have engendered opportunities for persons with disabilities to put their rights on the political agenda. The ongoing crises in Libya, the Syrian Arab Republic and Yemen, however, may be weakening DPO movements in those countries.

DPO federations also operate in some Arab countries and Governments often find them more efficient to work with than individual organizations. In Morocco, the Collectif pour la promotion des droits des personnes en situation de handicap (Association for the Promotion of the Rights of Persons with Disabilities) was created in 2006 and is made up of 32 organizations representing persons with various disabilities. It works to build the capacity of individual groups and lobbies to have the Convention put into practice around the country. The National Union of Associations for the Yemeni Disabled has almost 100 DPOs and NGOs in its network but has encountered difficulties in carrying out its coordinating role.⁶

Regional networks bringing together DPOs from various Arab countries include the Arab Organization of Persons with Disabilities and the Arab Forum for the Rights of Persons with Disabilities, both of which are based in Beirut. They promote intraregional cooperation and make sure that persons with disabilities in the Arab world are well represented in global forums. DPOs in Algeria, Mauritania and Morocco are part of the African Disability Forum, set up in Addis Ababa in 2014.

B. MEMBERSHIP AND REPRESENTATION

Some DPOs represent persons with disabilities in general, while others concentrate on those with a particular disability or on specific groups, such as women or children. The latter are important, given that priorities, barriers and concerns vary significantly depending on the nature of the disability. Cross-disability organizations, however, can be better placed to promote the rights of “people who all have been traditionally excluded and marginalized from society, and experience similar barriers”.⁷ Although most organizations in the Arab region, such as the Youth Association of the Blind (Lebanon) and the National Union of the Deaf (the Sudan), focus on specific types of disability, there are also cross-disability DPOs, such as the Palestinian General Union of People with Disability.

Certain groups of persons with disabilities, including women, rural dwellers and refugees, appear to be underrepresented in Arab DPO movements.

⁵ Axelsson and others, 2006, p. 59.

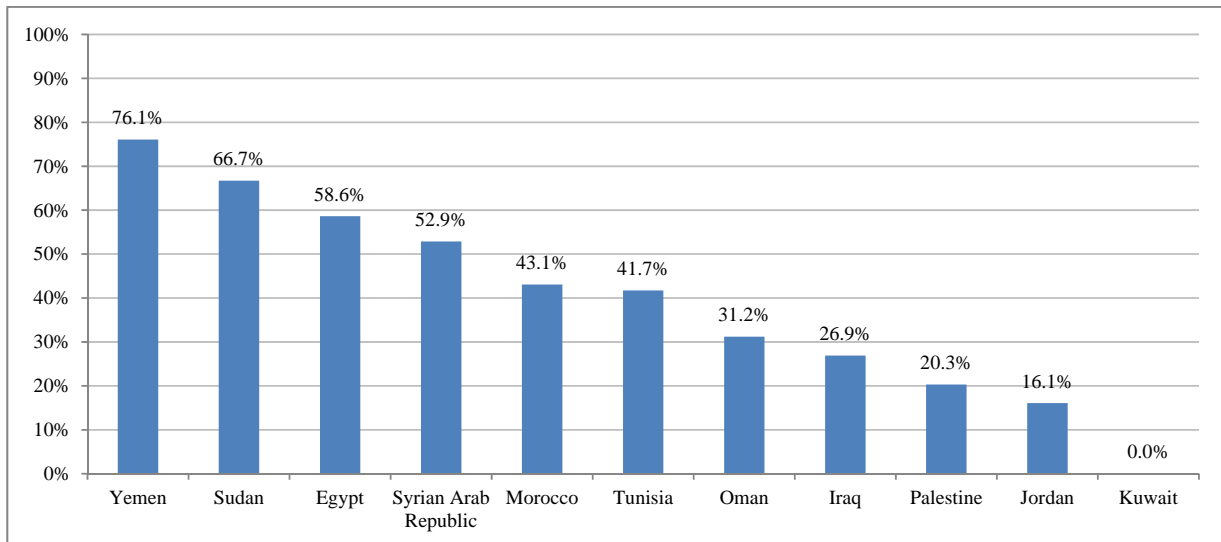
⁶ ESCWA, 2009, p. 10.

⁷ *Ibid.*, p. 14.

The United Nations Special Rapporteur on Disability from 2003 to 2009, Sheikha Hissa al-Thani, noted in 2006 that women with disabilities in the region lacked support organizations to “address their specific needs as women and as disabled persons”.⁸ Such women tend to experience discrimination on the basis of both their gender and disability, and thus need more effective representation.

Persons with disabilities living in rural areas are another group that risks exclusion from DPOs. Evidence from Yemen indicates that DPOs tend to be concentrated in cities and have difficulty representing rural people with disabilities.⁹ Most persons with disabilities in countries such as Egypt, the Sudan, the Syrian Arab Republic and Yemen live in rural areas (figure 1). Some DPOs have tried to address the problem by, for example, opening branches outside major urban areas, but little is known about the impact of such initiatives.

Figure 1. Proportion of persons with disabilities residing in rural areas in selected Arab countries



Source: ESCWA and the League of Arab States, 2014.

Refugees and internally displaced persons (IDPs) with disabilities, often among the most marginalized groups, also appear to be inadequately represented among Arab DPOs. Research in five displacement contexts around the world (including Jordan and Yemen) has found that: “In all the countries surveyed, there was little to no contact between refugees with disabilities and local disabled persons’ organizations (DPOs) and no attempts by local DPOs to integrate refugees with disabilities in their activities”.¹⁰ Given the spread of armed conflict and refugee flows in the Arab region, the issue urgently requires attention.

C. MAIN FOCUS AREAS AND ACTIVITIES

Arab DPOs engage in advocacy and awareness-raising campaigns; capacity-building; joint efforts with Governments on policy and legislation; and research and monitoring. Awareness-raising campaigns make up a major slice of DPO activities, relate to different groups of persons with disabilities and are often linked to the Convention. Examples include the efforts of DPOs in Jordan and Tunisia to promote the participation of

⁸ Al-Thani, 2006.

⁹ ESCWA, 2009, p. 13.

¹⁰ Women’s Refugee Commission, 2008, p. 4.

persons with disabilities in public life (box 1). Training and capacity-building are other key activities but information on target audiences and impact is lacking. Although 11 of the 12 ESCWA member States with national coordination mechanisms in 2013 reported that persons with disabilities were directly involved in their mechanisms (half the members of the Sudan's mechanism are by law supposed to be persons with disabilities), information on the role played by DPOs in them or other Government structures is scant.¹¹ Research and monitoring carried out by DPOs helps them to “become more successful at influencing positive policy and programmatic changes and use their time, energy and resources more effectively”.¹²

**Box 1. DPOs and participation by persons with disabilities in political life
in Jordan and Tunisia**

Article 29 of the Convention on the Rights of Persons with Disabilities sets forth the right of persons with disabilities to participate in political and public life, including through the provision of appropriate and accessible voting procedures, facilities and materials.

In 2010, DPOs in **Jordan** launched a project to promote the participation of persons with disabilities in national parliamentary elections. The project, led by a coalition called TAKAFO, involved researching existing legislation, working with policymakers and training volunteers to monitor the elections. The coalition succeeded in having accessibility improved and awareness raised among persons with disabilities of their voting rights. In spite of shortcomings, such as the failure to provide sign language interpretation at polling stations or to ensure that persons with disabilities can be accompanied by personal assistants when voting, the initiative was a practical demonstration of how DPOs can promote implementation of the Convention.

The activity of DPOs surged in **Tunisia** in the wake of the 2011 uprising. The Organisation tunisienne de défense des droits des personnes handicapées (Tunisian Organization for the Protection of the Rights of Persons with Disabilities) campaigned for the right of persons with disabilities to vote in elections to the National Constituent Assembly. It worked with the electoral authority to make polling booths accessible and provide sign language interpretation for television election programming. It also ran awareness-raising activities and provided observers on election day. Those efforts set an important precedent for reducing barriers and increasing the participation of voters with disabilities in Tunisia.

Sources: United States Agency for International Development (USAID), n.d.; International Disability Alliance, 2013.

Many Arab DPOs also provide services in such areas as education, rehabilitation and vocational training to persons with disabilities. Combining the roles of advocacy and service provision brings its own challenges. Focus on services and care can distract DPOs from the matter of rights, as has been the case with some DPOs in Egypt,¹³ and lead to a shift in responsibility for service provision from the State to civil society, as has occurred in Yemen, where DPOs and NGOs are the main service providers for persons with disabilities.¹⁴ Although cooperation between DPOs and the Committee on the Rights of Persons with Disabilities has been limited, they have on occasion participated in the preparation of States parties' periodic reports to the Committee, attended Committee meetings and side events and contributed to written submissions on thematic issues.

¹¹ ESCWA and the League of Arab States, 2014, p. 14.

¹² Leonard Cheshire Disability and Inclusive Development Centre, 2013, p. 6.

¹³ Axelsson and others, 2006, p. 41.

¹⁴ ESCWA, 2009, p. 12.

IV. RECOMMENDATIONS AND FURTHER RESEARCH

Organizations of persons with disabilities in the Arab region and around the world are likely to become increasingly active and prominent. In order to harness that momentum and boost their involvement in implementation of the Convention on the Rights of Persons with Disabilities, more research is needed in the following areas:

- The organizational capacities of DPOs and their ability to monitor implementation of the Convention: In-depth capacity assessments could contribute to a better understanding of their strengths and identify areas that require capacity-building;
- The composition and membership of DPOs and possible exclusion of any groups of persons with disabilities, such as women, rural dwellers, refugees and IDPs: More should be done to boost the representation of women in Arab DPOs and to ensure that they mainstream gender in all areas of their work;
- The work and impact of DPOs on legislative and policy processes: Research is needed on how DPOs work with Governments and on DPO federations. It may be worthwhile to explore any fragmentation in the DPO movement;
- DPO involvement and leadership in developing the disability research agenda: This means assisting Arab DPOs to conduct research and bridging gaps with other concerned parties, including Governments, academic institutions and international organizations. The result would contribute to higher quality research and, more importantly, the empowerment of persons with disabilities and their representative organizations in pursuing advocacy and respect for their rights.

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