



# Involvement and Participation of Organizations of Persons with Disabilities

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## Introduction

The last decade has witnessed an increase in the consultation of persons with disabilities through their representative organizations for the design and implementation of disability-related policies and programs, in accordance with CRPD-related provisions. Yet this consultation remains riddled with problems and these problems all lead to the same result: that persons with disabilities are still, to this day, excluded from the decision-making processes that ultimately protect their rights and affect their lives. This exclusion occurs, intentionally and unintentionally, across most concerned parties, whether governmental or non-governmental. Laws, policies, programs and services are often passed without consulting organizations representing persons with disabilities. Our needs are also often determined on our behalf, based on research and studies conducted by people without disabilities, whether officials or experts.

This paper was prepared and endorsed by a group of eight organizations of persons with disabilities (OPDs), to promote our right to be closely consulted and actively involved in all decisions related to persons with disabilities, in their diversity. It was prepared under the framework of a collaboration with the International Labour Organization "Towards Inclusive Social Protection in Lebanon".

The purpose of this position paper is to promote a meaningful consultation and active contribution of OPDS as a rights-based approach for governmental and non-governmental stakeholders when designing and implementing any new legislations, policies, regulations, procedures, and programs, whether mainstream or disability specific, as well as specialized services and/or other initiatives related to persons with disabilities. In addition, this paper aims to highlight practices and measures which ensure close consultation, active involvement and full participation of OPDS.

## A Rights-Based Obligation

The consultation of people with disabilities is a right enshrined in the Convention on the Rights of People with Disabilities (CRPD). Articles 4.3 and 33.3 of the CRPD stipulate the obligation of States parties to closely consult with and actively involve representative organizations of persons with disabilities in the development and implementation of legislations and policies, procedures, and programs and in other decision-making processes concerning issues relating to persons with disabilities. The CRPD also dictates that OPDs shall participate fully in the monitoring process of implementing the CRPD.

Lebanon ratified the CRPD and its protocol in February 2023. This means that Lebanon, with all its institutions, have a rights-based legal obligation to consult OPDs in all decisions related to persons with disabilities. These institutions include both governmental and non-governmental actors including parliament, central government, ministries, local authorities,

municipalities, UN agencies working in the country, international organizations, donors, civil society organizations and service providers.

## Consultation of OPDs in Lebanon

In Lebanon, there has been some good examples of international agencies who have started to adopt this approach in designing and implementing their disability related programs. This is best reflected in the consultation process which accompanied the development of the social protection strategy for Lebanon and in the regular consultations which accompany the design and implementation of the National Disability Allowance program.

Still, misconceptions and disempowering views towards persons with disabilities continue to be widespread at the national level. One of the most glaring and unfortunate manifestations of this reality is the ongoing debate amongst certain stakeholders, including parliament and the general public, to designate this population group, as we were an unidentified group that requires an adequate name to be bestowed upon it and its members. Moreover, laws, policies, programs and services are often passed without consulting organizations representing persons with disabilities. Our needs are often determined for us, according to what people without disabilities, whether officials or experts, believe to be true. Persons with disabilities are the ones best placed to identify their needs and issues as they are the ones who experience difficulties and barriers in their daily lives and identify the best solutions to remove such obstacles that prevent their participation on an equal basis with others.

Although many stakeholders claim to engage and consult OPDs, this consultation remains problematic as it does not amount yet to meaningful and effective participation and consultation. One of the most common practices observed is when consultations with one individual with a specific type of disability are considered sufficient in designing and implementing decisions and programs concerning all persons with disabilities. In fact, the individual in this case can only speak of his own personal experience and cannot reflect the experiences of all persons with disabilities in all their diversity. Another such practice is the expectation of organizations of persons with disabilities to play an advisory role within funded programs, on a purely voluntary basis, and without any compensation for the work provided. Finally, some stakeholders fail to distinguish between organizations of people with disabilities and organizations for people with disabilities. Organizations of people with disabilities are those that represent persons with disabilities, while organizations for people with disabilities are organizations that provide services to people with disabilities or organizations that work in the field of disability but are not run by people with disabilities.

An organization of persons with disabilities (OPD) has specific characteristics that legitimate its representative capacity of persons with disabilities. The organization should:

- a. be committed to and fully respect the principles of human rights as stated in the Convention (CRPD);
  - Respect for inherent dignity,
  - Respect for individual autonomy,
  - Respect for the freedom to make one's own choices,
  - Respect for independence of persons,
  - Non-discrimination,
  - Full and effective participation and inclusion in society,
  - Respect for difference and acceptance of persons with disabilities as part of human diversity,
  - Equality of opportunity,
  - Accessibility,
  - Equality between men and women,
  - Respect for the evolving capacities of children with disabilities.
- b. Express, promote, pursue and/or defend the rights of persons with disabilities in accordance with the provisions of the CRPD;
- c. Act in accordance with the principles of human rights and the policies promoted in the convention provisions;
- d. Have a clear voice in advocating for promoting, protecting, and implementing the rights of PWDS;
- e. Have a clear majority of membership for persons with disabilities;
- f. be led, governed, and controlled by majority of persons with disabilities;
- g. be represented by persons with disabilities who are elected or appointed by majority of persons with disabilities;
- h. not be affiliated to any non-representative organizations of persons with disabilities including affiliation to any political or religious entities, though they may be part of a mainstream umbrella or coalition of civil society organizations that do not necessarily advocate specifically for the rights of persons with disabilities;
- i. represent the diverse groups of persons with disabilities who form the organization's constituency. For example, if the constituency of the organization is only of men with disabilities, then this organization cannot represent all persons with disabilities.

It should be noted that organizations of parents of persons with intellectual disabilities and/or children with disabilities that have the above-mentioned aspects, are representative organizations of persons with disabilities. The role of parents in such organizations should be to assist and empower persons with disabilities to have a voice and to ensure and respect the right of persons with disabilities to be consulted and to express their own views.



as this is when the initiative will shape up and where OPDs will have a chance to influence its inclusiveness. The stakeholder must involve OPDs in the design, implementation, monitoring, and evaluation phases of the initiative. They must always consider their participation in meetings with other stakeholders involved in the intervention and inform them of the outcome of such consultations when they are not present on the table. In this case, reporting back on how OPDs' views and advice has fed into the decision-making process is also important. Moreover, when a policy, intervention or program's performance and impact are measured, OPDs must be involved in designing and conducting such activities. Informal and third-party monitoring of any intervention or policy by OPDs must be considered, as they can play a key role in assessing the intervention's impact on the dignity, autonomy, and self-governance of beneficiaries.

**Engagement of OPDs should be adequately compensated.** Any meaningful consultation of OPDs entails considerable time and effort on their part and must be compensated accordingly.