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# Learning About Meaningful Engagement with Organizations of Persons with Disabilities in Public Health Emergencies, Including COVID-19

**About this report**

This report presents learning from engagement of organizations of persons with disabilities (OPDs) in the COVID-19 response in Cambodia, Indonesia, Lao PDR, Malaysia, Myanmar, the Philippines and the Pacific. It presents important lessons for preparedness and response to future public health emergencies globally.

**Authors**

This report is authored by UNICEF. The project in the region of East Asia and the Pacific was led by Lieve Sabbe with significant inputs from Belly Lesmana, Darinne Jeong, Ben Wildfire and Kirstin Lange.

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Cover photo: A boy with Down Syndrome together with other boys all wearing a mask in a socially distanced classroom in Indonesia. © UNICEF/UN0353443/Wilander

# Learning About Meaningful Engagement with Organizations of Persons with Disabilities in Public Health Emergencies, Including COVID-19

A project implemented by UNICEF under the United Nations joint programme to support countries to design and implement disability-inclusive response and recovery planning for COVID-19.

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This report is authored by UNICEF. In East Asia and the Pacific Region, the project was led by Lieve Sabbe (regional programme specialist, children with disabilities), with significant inputs from Belly Lesmana (disability consultant), Darinne Jeong (child protection in emergencies and disability inclusion in emergencies consultant) and Ben Wildfire (knowledge management consultant). From the disability section at UNICEF Headquarters, Kirstin Lange (programme specialist, disability-inclusive humanitarian action) led the global project, while Margaret Waweru-Kihara (disability consultant) provided support with the desk review.

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## Acronyms

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BNPB	Indonesian National Board for Disaster Management (Indonesian: <i>Badan Nasional Penanggulangan Bencana</i> )
BPBD	Provincial Disaster Management Agency
COVID-19	coronavirus disease 2019
CRPD	Convention on the Rights of Persons with Disabilities
CSO	civil society organization
FGD	focus group discussion
Gol	Government of Indonesia
GoM	Government of Malaysia
HI	Humanity & Inclusion
IASC	Inter-Agency Standing Committee
INGO	international non-governmental organization
KII	key informant interview
MoSA	Ministry of Social Affairs
MoSVY	Ministry of Social Affairs, Veterans and Youth
NGO	non-governmental organization
OPD	organization of people with disabilities
UNICEF	United Nations Children's Fund
UNPRPD	United Nations Partnership on the Rights of Persons with Disabilities
WASH	water, sanitation and hygiene



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# 1 Background

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UNICEF, together with the International Labour Organization, United Nations Development Programme, United Nations Educational, Scientific and Cultural Organization, World Health Organization, United Nations Entity for Gender Equality and the Empowerment of Women, United Nations Population Fund, United Nations Department of Economic and Social Affairs, and the Office of the High Commissioner for Human Rights, is implementing a United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) project to support countries in designing and implementing disability-inclusive response and recovery planning for coronavirus disease 2019 (COVID-19). Throughout this project, UNICEF has documented examples of good practice and learnings from partnerships with organizations of people with disabilities (OPDs) in public health emergencies, including COVID-19.

The objectives of this initiative are to gain a better understanding of the factors that facilitate effective partnerships between humanitarian actors and local, regional and national OPDs, and the challenges to be addressed. This learning will be shared across UNICEF and with other United Nations entity partners in the UNPRPD project, as well as with OPD networks, including the International Disability Alliance. It is expected that this learning will contribute to efforts to strengthen disability-inclusive humanitarian action, as well as informing efforts towards strengthening localization. The target audience for this report includes OPDs and humanitarian actors at global, regional and country levels.

As part of this initiative, UNICEF East Asia and the Pacific Regional Office has undertaken a regional 'deep dive', considering experiences in Cambodia, Indonesia, the Lao People's Democratic Republic, Malaysia, Myanmar, the Philippines and the Pacific.

## 2 Frameworks and guidance on “nothing about us without us”

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This chapter summarizes normative frameworks, guidance and learning related to the participation of OPDs in humanitarian action. This is intended as a background to the documentation of good practice and learning regarding OPD engagement in the COVID-19 response. This is being undertaken by UNICEF under the UNPRPD-funded United Nations joint programme to support countries to design and implement disability-inclusive response and recovery planning for COVID-19.

### 2.1 Normative framework

#### 2.1.1 *Convention on the Rights of Persons with Disabilities*

The core normative framework, the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol ([A/RES/61/106](#)) was adopted on 13 December 2006 at the United Nations Headquarters in New York and opened for signature on 30 March 2007. It currently has 182 States parties.

The CRPD, in its general obligations (Article 4), set out the obligation of States parties, consistent with the human rights principle of participation, to closely consult and actively involve persons with disabilities – including children with disabilities – through their representative organizations, in all decision-making processes concerning issues relating to persons with disabilities. More specifically:

- Article 32 refers to the obligation of states to partner with OPDs in international cooperation to support national efforts to realize the purpose and objectives of the CRPD
- Article 33 calls for participation of OPDs in monitoring CRPD implementation.

Article 7 of the CRPD requires State parties to ensure that children with disabilities have the right to freely express their views on all matters affecting them. In addition, Article 23 of the Convention on the Rights of the Child demands states ensure that children with disabilities participate actively in the community. As stated by the Committee on the Rights of the Child in its general comment no. 9, measures taken to fulfil the rights of children with disabilities should aim to ensure their full inclusion in society (CRC/C/GC/9, para. 11).

The Committee on the Rights of Persons with Disabilities’ [general comment no. 7](#) on the participation of persons with disabilities elaborates on the

role of OPDs as set out in the CRPD.<sup>1</sup> The general comment states that participation by OPDs is both consistent with the human rights-based approach in public decision-making processes and ensures good governance and social accountability. It also recognizes the value of participation by OPDs because of their lived experiences and knowledge of the rights to be implemented.

The Committee on the Rights of Persons with Disabilities distinguishes OPDs from other civil society organizations (CSOs), such as those ‘for’ persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities. According to the general comment, OPDs are “rooted, committed to and fully respect the principles and rights recognized in the Convention. They can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves.” OPDs are further defined as:

- Being established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities
- Employing, being represented by, entrusting or specifically nominating/appointing persons with disabilities themselves
- Not affiliated, in the majority of cases, to any political party and being independent from public authorities and any other non-governmental organizations (NGOs) of which they might be members.

The general comment also recognizes diversity among the constituencies of OPDs, in that:

- They may represent one or more constituencies based on actual or perceived impairment
- They represent groups of persons with disabilities, reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status)
- They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities)
- They can be local, national, regional or international in scope
- They can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice.

The Committee on the Rights of Persons with Disabilities further identifies the requirements of OPDs that enable them to participate meaningfully, including:

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1 [Convention on the Rights of Persons with Disabilities. General Comment No. 7 \(2018\) on the Participation of Persons with Disabilities, Including Children with Disabilities, through their Representative Organizations, in the Implementation and Monitoring of the Convention. United Nations, New York, November 2018.](#)

- Access to all relevant information, including the websites of public bodies, through accessible digital formats and reasonable accommodation when required, such as the provision of sign language interpreters, easy read text and plain language, Braille and tactile communication
- Access to all facilities and procedures related to public decision-making and consultation including buildings, transportation, education, information and communications in the person with a disability's own language, including new information technologies and systems
- Access to consultation processes, through accessible communication and support, funding and reasonable accommodation as appropriate and requested
- Organizations of persons with sensory and intellectual impairments, including organizations of self-advocates and organizations of persons with psychosocial disabilities, should be provided with meeting assistants and support persons, information in accessible formats, sign language interpretation, guide interpreters for deafblind persons and/or captioning during public debates.

Specifically in regard to children, the general comment reaffirms that children with disabilities are rights holders who can play an active role in their communities and society. It sets out measures that should be taken in order to support children with disabilities in their decision-making, including child-friendly information, adequate support for self-advocacy, and disability and age-appropriate assistance and procedures.

### ***2.1.2 Report of the Special Rapporteur on the rights of persons with disabilities***

The July 2020 [report of the Special Rapporteur on the rights of persons with disabilities](#) calls for participation by persons with disabilities and OPDs as both agents and beneficiaries of international cooperation, including planning, implementation and monitoring, "given that they know best the barriers that they face and the impact that such barriers have on their lives." The report reaffirmed that states and multilateral and private donors must closely consult and actively involve persons with disabilities and their organizations in all efforts related to international cooperation. This includes the identification of priorities, policy development, implementation and evaluation, and international cooperation to respond to the COVID-19 pandemic and its socioeconomic impacts.

The report also recognizes the limited availability of literature on whether and how such consultations take place in the area of international cooperation.

### ***2.1.3 Thematic study on the rights of persons with disabilities under Article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies***

This [thematic study](#) by the Office of the High Commissioner for Human Rights, presented at the thirty-fifth session of the Human Rights Council in 2015, sets

out standards for the human rights of persons with disabilities in situations of risk and humanitarian emergencies.

The study identified that “in order to improve humanitarian response effectiveness with regard to persons with disabilities, it is crucial to foster collaboration between local, national and international organizations working on disability.” It emphasized the importance of substantive dialogue and dissemination of good practices among persons with disabilities and their representative organizations, and those working on risk and humanitarian emergencies.

#### **2.1.4 Charter on Inclusion of Persons with Disabilities in Humanitarian Action**

The [charter](#) was launched at the World Humanitarian Summit in 2016 and endorsed by a wide range of states, multilateral agencies, NGOs and OPDs. The charter includes a commitment by signatories to “promote meaningful involvement of persons with disabilities and their representative organizations in the needs assessment, design, implementation, coordination, monitoring and evaluation of humanitarian preparedness and response programs and draw from their leadership, skills, experience and other capabilities to ensure their active participation in decision making and planning processes including in appropriate coordination mechanisms.”

## **2.2 Guidance**

### **2.2.1 Inter-Agency Standing Committee Guidelines on including persons with disabilities in humanitarian action**

These Inter-Agency Standing Committee ([IASC guidelines](#)) were launched in 2019, following a participatory process of development that brought together OPDs and humanitarian actors. The guidelines set out participation by persons with disabilities and their representative organizations as one of the key approaches to programming, or ‘must dos’ of humanitarian action.

The guidelines include a chapter dedicated to partnerships with and empowerment of OPDs. A number of examples of potential roles of OPDs in humanitarian action are set out, including:

- Acting as focal points in their communities
- Providing valuable information on where persons with disabilities are located, their situations, barriers that prevent them from accessing humanitarian assistance, threats to them and violations of their rights
- Providing technical support on disability inclusion to humanitarian actors
- Providing targeted services to persons with disabilities, often through a peer-support model.

The guidelines also contain a chapter on stakeholders' roles and responsibilities, setting out in more detail the roles and responsibilities of OPDs, such as:

- Advocating and raising awareness of the rights of persons with disabilities, including through training
- Participating in and promoting inclusiveness of needs assessment processes
- Reaching out to affected persons with disabilities and including them in OPD networks
- Advising on accessibility
- Collaborating with humanitarian actors to document good practice and learning on inclusion of persons with disabilities.

The guidelines also recognize challenges to partnerships between OPDs and humanitarian actors, including limited experience engaging in humanitarian action on the part of OPDs and limited knowledge of the disability movement and misconceptions about persons with disabilities on the part of humanitarian actors. In situations where local OPDs do not have the mandate or capacity to engage in humanitarian action, humanitarian actors are advised to reach out to regional or global OPD networks. Where OPDs do not exist, have been weakened by the crisis or do not represent affected populations, the guidelines recommend that humanitarian actors:

- Engage with persons with disabilities and their families and encourage them to participate in consultation processes and decision-making bodies
- Identify qualified individuals who have a range of disabilities, and are of different ages and genders, and recruit them as staff members and volunteers
- Set up and encourage the formation of formal and informal groups (such as peer-support groups of persons with disabilities and their families) and build the capacity of these groups to represent their constituencies
- In the context of forced displacement, invite host community OPDs to support the establishment of networks of persons with disabilities among refugees and other displaced populations, and encourage and support OPDs to include refugees and other displaced persons in their networks.

Each sectoral chapter of the guidelines sets out actions more specific to that sector on partnering with OPDs.

### **2.2.2 Humanitarian inclusion standards**

The humanitarian inclusion standards for older people and people with disabilities are companion standards to the Sphere Handbook<sup>2</sup> and are designed both to strengthen the accountability of humanitarian actors to older

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2 Sphere Association, *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response*, 4th ed., Geneva, Switzerland, 2018.

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people and people with disabilities and to support the participation of older people and people with disabilities in humanitarian action.

One of the nine key humanitarian inclusion standards is knowledge and participation. That is, that older people and people with disabilities know their rights and entitlements and that they participate in decisions that affect their lives. This inclusion standard contains two key actions:

- Provide accessible information about rights and entitlements, and work with OPDs to design and deliver this information
- Promote the meaningful participation of older people and people with disabilities in decision-making, including working with OPDs to identify and remove barriers that may prevent them from participating in decision-making.

Participation by OPDs is further addressed in the key inclusion standard on coordination. This requires that older people and people with disabilities access and participate in humanitarian assistance that is coordinated and complementary. This inclusion standard calls for support to be given to people with disabilities and their representative organizations so that they can participate meaningfully in inter-agency coordination mechanisms, including meetings and working groups. This can be achieved through:

- Holding preparatory meetings with groups of people with disabilities and their representative organizations to explain how the coordination mechanisms work, how they can participate and what will be expected of them
- Supporting these groups to plan how they will input into the coordination meetings
- Involving women and men equally, and involving people with different types of disabilities, including people with psychosocial or intellectual disabilities
- Ensuring accessibility of meeting facilities and communication.

The humanitarian inclusion standards also set out tips for humanitarian actors to map OPDs, including:

- Identifying their priorities for humanitarian action, their strengths, capacities and areas that need to be strengthened
- Asking them about their role in the community
- Asking them who they represent, how they collect information from the crisis-affected population and how they promote gender equality and diversity in their work
- Looking for organizations that represent different types of disability, all genders and ages, and different at-risk groups (such as refugees, migrants or people from ethnic minorities).

The sector standards also contain numerous references to participation by OPDs in more sector-specific activities; for example, in the water, sanitation



and hygiene (WASH) sector, working with OPDs to advise on cultural preferences for WASH facilities and reaching out to more isolated people with disabilities, and supporting their participation in WASH-related coordination and decision-making mechanisms, such as WASH clusters or water management committees.

### **2.2.3 UNICEF Guidance on including children with disabilities in humanitarian action**

A set of six UNICEF guidance booklets on [including children with disabilities in humanitarian action](#) provide practical advice on inclusion across five key sectors and include one booklet giving general guidance.

The general guidance booklet contains advice that can be applied across sectors and gives a sense of the diversity of roles that OPDs may have in humanitarian action.

- OPDs may have data on children with disabilities and they can be a good resource in the process of collecting data on children with disabilities
- Engage OPDs in focus group discussions (FGDs) to promote inclusive planning and budgeting processes
- Disability expertise can be mobilized through establishing new partnerships with OPDs
- Include OPD members in rosters of experts and pools of trainers and reach out to OPDs to share recruitment information and identify persons with disabilities who may be qualified for staff positions
- Organize workshops to engage OPDs in the design, review and dissemination of communication materials
- Work with OPDs to facilitate access to assistive devices
- Collaborate with OPDs to reach out to children with disabilities who may not be in school or are isolated in their homes.

The UNICEF guidance also recognizes the importance of supporting OPDs to enable them to contribute in a meaningful way to humanitarian action. For example, inviting OPDs to trainings organized with humanitarian partners to familiarize them with the humanitarian system architecture, the humanitarian programme cycle, and international response processes and tools.

### **2.2.4 COVID-19 response**

A number of guidance documents about the response to COVID-19 highlight the important role of OPDs.

The United Nations Secretary-General *Policy Brief: A disability-inclusive response to COVID-19* includes four overarching areas of action. One of these is to ensure meaningful consultation with, and active participation of,





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A boy with a visual impairment drawing with a crayon.

persons with disabilities and their representative organizations in all stages of the COVID-19 response and recovery. The brief identifies the contributions that persons with disabilities can make in finding innovative and creative solutions, due to their “experience of thriving in situations of isolation and alternate working arrangements that can offer models for navigating the current situation.” More broadly, the brief sets out that partnership with OPDs improves effectiveness and accountability.

The *IASC Key Messages on Applying IASC Guidelines on Disability in the COVID-19 Response* identifies roles for OPDs both in addressing the health and the socioeconomic impacts of the pandemic. Roles identified include:

- Engaging in developing COVID-19 outbreak preparedness and response plans (including assessing and minimizing risks) and ensuring accessibility of the public health response (including facilities identified and referral systems established for screening, isolation and treatment, as well as risk communications and WASH facilities)
- Engaging in assessing social and economic impacts and in developing or adapting response plans.

The key messages further emphasize ensuring that there is full diversity (including in age, gender and impairment type) in the representation of persons with disabilities by OPDs engaging in the COVID-19 response.

The UNICEF guidance *COVID-19 Response: Considerations for children and adults with disabilities* sets out an overarching action to “reach out to local OPDs and engage with them at every stage of the response, from the identification of persons with disabilities and development of key messages to building capacity on disability inclusion among responders.” The guidance also provides examples of how OPDs can be engaged, including in designing prevention and response plans, participating in local and national coordination mechanisms and addressing social norms that may result in persons with disabilities being de-prioritized in terms of access to health care.

## 2.3 Good practice and lessons learned

### 2.3.1 Challenges

A number of studies have highlighted challenges to OPD participation in humanitarian contexts.

- While participation by OPDs is increasing overall, persons with psychosocial disabilities, persons with intellectual disabilities, persons with deafblindness, deaf persons, women with disabilities and indigenous persons with disabilities are still largely left out of consultation and decision-making processes.<sup>3</sup>
- Preconditions for participation are not met, such as accessibility of the physical environment, accessibility of information and communication; there remain poor attitudes and knowledge about how to engage with persons with disabilities and a lack of funding for reasonable accommodation.<sup>4</sup>
- Financial support remains the biggest challenge for OPDs to exist as representative organizations; because of the number, complexity and lack of coordination between different processes and stakeholders soliciting inputs from them, OPDs face significant costs when choosing to engage with different agencies.<sup>5</sup>
- Formalized processes within the humanitarian programme cycle are constrained by limited time and budgets, and as such they are rarely conducive to open dialogue and reflection. This often results in humanitarian agencies bypassing OPDs.<sup>6</sup>
- Emergency response is often coordinated or managed by humanitarian surge teams, which often arrive at a disaster response with limited understanding of the complexities of local contexts, languages and cultural norms, and thus have less capacity to engage local OPDs. Even where local national teams

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3 [International Disability Alliance, \*Increasingly Consulted, but not yet Participating\*, IDA, November 2020.](#)

4 [Ibid.](#)

5 [Ibid.](#)

6 [Al Jubeh, Kathy and Alradi Abdalla, 'A Participation Revolution': Creating genuine dialogue and partnerships between humanitarian actors and the disability movement, Humanitarian Practice Network, October 2020. <https://odihpn.org/magazine/a-participation-revolution-creating-genuine-dialogue-and-partnerships-between-humanitarian-actors-and-the-disability-movement>](#)

are engaged, they do not always have an understanding of the complexity or diversity of local disability movements, much less trusted relationships with these groups.<sup>7</sup>

- OPDs are primarily consulted on disability-specific issues, such as disability policies, and they are mostly funded through international non-governmental organizations (INGOs) focused on disability, indicating that disability is not yet considered a cross-cutting issue.<sup>8</sup>

### 2.3.2 Good practice examples

A number of examples of partnership between OPDs and humanitarian actors have been documented, including:

- OPDs from host communities building peer networks for refugees with disabilities in Lebanon<sup>9</sup>
- Partnership with OPDs in natural disaster response in Nepal<sup>10</sup>
- OPD engagement in refugee response in Greece.<sup>11</sup>

A recent report by the inter-agency working group on disability-inclusive COVID-19 response and recovery documented a number of examples of OPD engagement in the COVID-19 response in South Sudan and Latin America. The report identified that OPDs have a range of roles in the COVID-19 response, including:

- Supporting inclusive needs assessment that identifies the risks faced by and the needs and priorities of persons with disabilities
- Supporting the delivery of community awareness and risk communication
- Advocating with local or national authorities on the rights of persons with disabilities in the context of COVID-19 restrictions
- Engaging with those who are hard to reach, including displaced persons with disabilities.

### 2.3.3 Recommendations

A key recommendation is the creation of spaces for dialogue and mutual learning between OPDs and humanitarian actors, as described by Al Jubeh and Abdalla in 2020, “if we want a participation revolution, and want to open

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7 Al Jubeh, Kathy and Alradi Abdalla, *A Participation Revolution’: Creating genuine dialogue and partnerships between humanitarian actors and the disability movement*, Humanitarian Practice Network, October 2020. <https://odihpn.org/magazine/a-participation-revolution-creating-genuine-dialogue-and-partnerships-between-humanitarian-actors-and-the-disability-movement>

8 *Increasingly Consulted, but not yet Participating*.

9 CBM International, Humanity & Inclusion and the International Disability Alliance, *Case studies collection 2019: Inclusion of persons with disabilities in humanitarian action*, CBM, HI and IDA, 2019.

10 *Case studies collection 2019: Inclusion of persons with disabilities in humanitarian action*.

11 *Ibid.*

up more innovative dialogue that allows for meaningful participation, we need genuine spaces and opportunities, both formal and informal. This requires the creation of spaces where the traditional power dynamics of donor and recipient are upended.”<sup>12</sup>

In addition to space for dialogue, it is also recommended that partnership with OPDs is linked with empowerment and capacity-building to equip OPDs with the resources (including skills, information, insights, data and evidence) they need to prioritize and identify key windows of opportunity for influence and to strategize their inputs to achieve greater impact.<sup>13,14</sup>

It has also been identified that, where there are pre-existing partnerships between humanitarian actors and OPDs, the response is more efficient at the onset of humanitarian emergencies.<sup>15</sup> It is recommended that partnership and collaboration with a range of persons with disabilities and OPDs from different constituencies, including women, indigenous persons and persons with psychosocial and intellectual disabilities, can better address the multiple and intersecting forms of discrimination they face.<sup>16</sup>

The International Disability Alliance has specific recommendations for United Nations entities to “act as allies of OPDs to facilitate their strategic engagement with governments; support OPDs to strategize their contributions, model by example through support effective and empowering OPD participation; inform OPDs about the work of the United Nations; actively support the implementation of the United Nations Disability Inclusion Strategy (UNDIS); ensure accessibility of all consultations organised by the United Nations; ensure OPDs have access to funding opportunities; hire persons with disabilities and train United Nations staff on the rights of persons with disabilities; guarantee and support the participation of the diversity of persons with disabilities through OPDs; and monitor and account for progress under indicator 5 of the UNDIS.”<sup>17</sup>

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12 Al Jubeh, Kathy and Alradi Abdalla, *'A Participation Revolution': Creating genuine dialogue and partnerships between humanitarian actors and the disability movement*, Humanitarian Practice Network, October 2020.

13 *Increasingly Consulted, but not yet Participating*.

14 *Case studies collection 2019: Inclusion of persons with disabilities in humanitarian action*.

15 *Ibid.*

16 *Case studies collection 2019: Inclusion of persons with disabilities in humanitarian action*.

17 *Increasingly Consulted, but not yet Participating*.

### 3 Learning from the field about meaningful engagement of OPDs in public health emergencies

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This chapter contains recommendations resulting from a ‘deep dive’ analysis in East Asia and the Pacific Region. This aims to support the meaningful engagement of OPDs in strategic advocacy and coordination platforms, to strengthen disability-inclusive response and recovery planning.

The findings that have led to these recommendations can be found in the case studies presented in the following chapters.

#### **Recommendation 1: Develop a reliable database of OPDs, parent groups and potential coalitions**

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**Intended for:** United Nations INGOs/NGOs

##### **Concrete actions:**

- Map OPDs, parent groups and coalitions, and develop a database at national/subnational level
- Identify OPDs with an established network of government authorities and communities of people with disabilities
- Identify any existing coordinating bodies that include OPDs at national or subnational level
- Seize the opportunity presented by remote platforms established under COVID-19 to reach more virtual OPD networks; it is important to become familiar with accessibility features to accommodate the requirements of persons with disabilities in virtual meetings

#### **Recommendation 2: Provide opportunities and entry points for OPDs to enter into partnership with humanitarian actors**

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**Intended for:** United Nations INGOs/NGOs

##### **Concrete actions:**

- Make disability inclusion an overarching approach in emergency management processes (e.g., consultation activities or co-creation process with OPDs)
- Integrate disability inclusion and requirements for engagement with OPDs in emergency policies and plans, as well as in organizational core strategic documents, such as a multi-year programme strategy document and policy
- Foresee dedicated budget for disability inclusion and formal partnership with OPDs through mainstreamed and targeted activities (twin-track approach), which aim towards realizing the rights of persons with disabilities

- United Nations agencies and INGOs/NGOs should have a dedicated disability specialist or experienced disability focal points to facilitate connections, ensure accessibility for documents and meetings, and provide opportunities for OPDs to deliver training to humanitarian actors on the rights of persons with disabilities
- Proactively engage the most at-risk populations, e.g., people with intellectual disabilities or children with disabilities (including through parent groups), who may not be well represented by OPDs

### **Recommendation 3: Build capacities of OPDs through development of humanitarian knowledge and skills**

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**Intended for:** United Nations INGOs/NGOs

#### **Concrete actions:**

- Provide trainings on child rights, humanitarian standards and procedures (e.g., Core Humanitarian Standard, Sphere Project)
- When a new programmatic approach is introduced by an NGO or the Humanitarian Country Team, support OPDs to fully understand the approach before delivering the response activities

### **Recommendation 4: Provide information on partnership procedures and programme management standards to OPDs**

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**Intended for:** United Nations INGOs/NGOs

#### **Concrete actions:**

- Support OPDs to understand the mandate of each United Nations agency and their respective partnership requirements; e.g., to explicitly represent and respond to issues around children with disabilities and women with disabilities is a condition to partner with UNICEF
- Provide all documentation and procedures on partnership and funding programmes in accessible formats
- Invest sufficiently in training on requirements for partnership related to data collection, budget management and other procedures, including reporting
- Identify strategically based CSOs, to facilitate an initial and sustained engagement with OPDs; to formalize such engagement, United Nations agencies may establish or adapt policies for partnership with CSO consortia to facilitate formal partnerships with local actors, including OPDs



## **Recommendation 5: Support and coordinate with OPDs in advocacy for more disability-inclusive national emergency preparedness and response**

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**Intended for:** United Nations INGOs/NGOs policy makers

### **Concrete actions:**

- Facilitate linkages of OPD coalitions with policymakers at national and local levels, including formal governmental structures responsible for disability, to ensure sustainability of disability-inclusive programming and meaningful engagement of OPDs, especially for smaller OPDs with less visibility
- Invite (and encourage) OPD participation in meetings with policymakers at national or local level and ensure accessibility of communication
- Support existing OPDs' advocacy initiatives
- Build capacity of OPDs on advocating for the most excluded and at-risk groups
- Engage OPDs as trainers on the rights of persons with disabilities for national emergency responders and authorities

## **Recommendation 6: Support OPDs in boosting their visibility to humanitarian actors**

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**Intended for:** United Nations INGOs/NGOs policy makers

### **Concrete actions:**

- Disseminate information about OPD work and results and acknowledge the inputs of OPDs in larger processes
- Ensure that people with disabilities can participate fully in consultations by providing accessible information, consultation platforms and meeting facilities, and providing reasonable accommodation for meetings and workshops
- Promote the participation of OPDs in emergency preparedness and response processes with policymakers and humanitarian actors, including in situations not specifically about disability

Note: For this publication, UNICEF has documented engagement of both OPDs and parent groups for the development of the above recommendations. Acknowledging that as per the CRPD definition, parent groups are not led by persons with disabilities, including them in the research was instrumental to also address issues around children with disabilities. The role of parents and families is key when engaging with children with disabilities.

## 4 Deep dive research in East Asia and the Pacific Region

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### 4.1 About the qualitative research

#### 4.1.1 Methodology

In order to gather in-depth insights into the engagement with OPDs in humanitarian actions, UNICEF undertook qualitative research in Indonesia and Malaysia using the following tools:

- Key informant interviews (KIIs) with 12 people (6 females) for 7 Indonesian OPDs and 2 groups of parents of children with disabilities
- KIIs with eight people (four females) for four Malaysian OPDs and one group of parents of children with disabilities
- 2 FGDs with 11 participants (5 females) for Indonesian OPDs and groups of parents of children with disabilities
- One FGD with eight participants (five females) for Malaysian OPDs and groups of parents of children with disabilities
- KIIs with three UNICEF Indonesia Country Office staff (one female)
- KIIs with three UNICEF Malaysia Country Office staff (one female)
- Five persons from UNICEF and humanitarian actors participated in an online survey.

The questionnaires covered the core aspects of meaningful engagement that were discussed in the humanitarian frameworks and existing guidance.

To describe the level of participation of OPDs, the researcher used the ladder of citizen participation.<sup>18</sup> This has been in use since the 1960s to monitor participation in a development context (*see Figure 1*).

Once the findings were collected and analysed, the participants were given the opportunity in a workshop to validate their stories and findings of how they perceived and made sense of their experiences.

The secondary data were gathered by carrying out a desk study to review emergency and COVID-19 response-related information conducted by UNICEF Indonesia, UNICEF Malaysia, OPDs in Indonesia and OPDs in Malaysia. Laws and regulations of the Government of Indonesia (GoI) and the Government of Malaysia (GoM) were also reviewed.

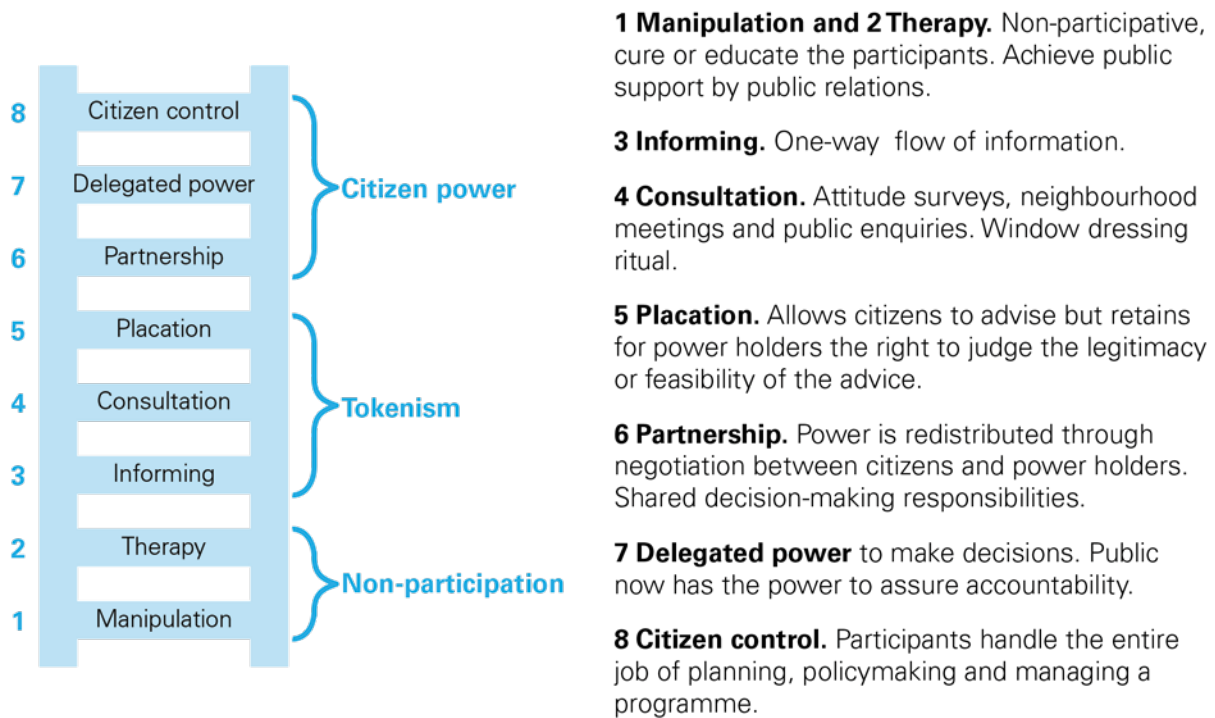
Besides the qualitative research in Indonesia and Malaysia, UNICEF collected case studies in Cambodia, Lao People's Democratic Republic, Myanmar, the Philippines and the Pacific. These are shared in Sections 4.3 to 4.6.

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18 Arnstein, Sherry R. 'A Ladder of Citizen Participation', *Journal of the American Institute of Planners*, vol. 35, no. 4, July 1969, pp. 216–224.



**Figure 1.** Ladder of citizen participation



#### 4.1.2 Respondent selection

The participants for KII and FGD in Indonesia were selected from a database of OPDs from the Indonesia Country Office and emergency response documents. The participants were selected to ensure representation of different types of disability. The Indonesian participants came from national and local levels, representing both urban and rural areas.

The participants for KII and FGD in Malaysia were selected from a database of OPDs from the Malaysia Country Office. Participants were selected based upon the variety of disabilities represented by their organizations represented, nationwide representation and/or their connection to parent networks of children with disabilities.

#### 4.1.3 Limitations of the qualitative research

The strength of the research is that the OPDs in both Indonesia and Malaysia were very responsive in providing information through the KIIs and FGDs, including in the validation workshop. Nevertheless, there were several major limitations in this study that could be addressed in future research.

- Sample size: In Malaysia, movement restrictions due to COVID-19 meant that several participants could not take part in the interview.
- Sampling criteria: After interpretation of the Indonesian findings, it was found that one participant did not match the OPD criteria; subsequently, the interpretation had to be reanalysed to some extent to exclude this participant.
- Limited access to data: There was a low response rate to the survey aimed at UNICEF staff and humanitarian actors.
- Data collection process: The interview of two OPDs in Malaysia took place after the validation workshop; these two participants may be biased by the conclusions and recommendations validated earlier in the FGD; also, the inputs shared by these two informants was not validated by the other OPDs.
- Lack of previous studies: The literature on humanitarian response-related information in Malaysia is very limited since it is classed as being in a development context and does not have a high risk of natural disasters to respond to regularly.

## 4.2 Deep dive in Indonesia and Malaysia

### 4.2.1 Context in Indonesia

In the disaster context, Indonesia is one of the five countries that has been most frequently hit by natural hazards over the last ten years.<sup>19</sup> About 80 per cent of Indonesia has a tropical climate, which causes frequent flooding, landslides, extreme weather, drought, land and forest fires, as well as abrasion and extreme waves. Besides climate-related disasters, due to rapid development and population growth, Indonesia also has the potential to experience industrial accidents and disease outbreaks. When COVID-19 hit the country, children with disabilities were among the most excluded groups in Indonesia, in terms of access to education. They faced even more significant challenges to accessing high-quality education than before the pandemic.<sup>20</sup>

In the policy context, Indonesia's framework for humanitarian response is grounded in a rights-based approach. Firstly, in regard to regulation and policies to ensure the rights of people with disabilities, the Gol passed Law No. 8 /2016 to replace Law No. 4/1997, which shifted the paradigm from the charity approach to the rights-based approach. The new law follows the principles in the CRPD, which was ratified in 2011 by the Gol. The ratification made the Gol commit to the eradication of discrimination against people with disabilities and to actively work to support and provide services to people with disabilities. It also follows the principle that public programmes have to be inclusive and accessible to people with disabilities. Currently, the law and the

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19 International Federation of Red Cross and Red Crescent Societies, *World Disasters Report*, IFRC, Geneva, 2018.

20 Fathur Rohman, Y. and V. Sumarlis, *Research Report: Students with disabilities during the COVID-19 pandemic*, Wahana Inklusi Indonesia and UNICEF, 2019.



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A young man with a physical disability waits to receive a COVID-19 vaccination in Cambodia.

implementing regulations under it promote the participation of people with disabilities in the decision-making process, including in disaster management.

Secondly, in disaster response and mitigation, the Gol passed Law No. 24/2007 on disaster management and adopted implementing regulations. Presidential Regulation No. 8/2008 established the Indonesian National Board for Disaster Management (BNPB). To ensure the rights of people with disabilities in a disaster context, the BNPB passed Regulation No. 14/2014 (to establish a disability unit service. The disability unit service is a government disability-related counterpart in providing recommendations in disaster management, developing plans and budgets, monitoring and evaluating the implementation of policies and programmes, and identifying and ensuring that the needs of people with disabilities are met. The same regulation also stipulates a community-based disaster reduction forum to invite representations of OPDs in its structure. To ensure clear coordination, leadership and accountability in the area of humanitarian action, Indonesia adopts the United Nations cluster approach, with protection and shelter clusters in place. In the Gol cluster system, the BNPB provides an opportunity for OPDs to participate in disaster response. In the response to the COVID-19 pandemic, the Ministry of Social Affairs (MoSA) is the responsible for managing this.

Thirdly, in response to the COVID-19 pandemic, Indonesia has formed an ad hoc body called the Task Force of COVID-19 Handling, which is coordinated by the Head of the BNPB. This body's main tasks are to implement and control strategic policies related to responding to the COVID-19 pandemic quickly and accurately, and resolving any issues.

#### **4.2.2 Context in Malaysia**

Malaysia is located on the outer edge the Pacific 'ring of fire' and south of major typhoon paths. It is relatively stable and has had no major, nationwide disasters since the 2004 Indian Ocean earthquake and tsunami. However, Malaysia is often affected by other natural disasters such as floods, landslides, haze, earthquakes and other human-made disasters, as well as, rarely, droughts and tsunami. Annually, floods account for the most frequent and significant damage, and are responsible for a significant number of lost human lives, disease epidemics, property and crop damage, and other losses.<sup>21</sup>

In the context of regulation and policy, Malaysia is a federation with a constitutional monarchy and federal law. However, at the state level, Malaysia also adopts Syariah and customary law. The context of disability is stated in the Article 8(2) of the federal law with regard to people with disabilities. Despite an article prohibiting discrimination on various grounds, there is no explicit prohibition of discrimination against those with disabilities.<sup>22</sup>

GoM ratified the CRPD in 2010 and the 2008 Persons with Disabilities Act. Through this act, GoM formally acknowledges the need to reduce barriers to participation, as well as to adopt a rights-based approach towards disability. The Persons with Disabilities Act mandates the GoM to establish a national council for persons with disabilities, which has obligations to oversee, coordinate and monitor the implementation of national policies and plans of action related to persons with disabilities.<sup>23</sup> The Persons with Disabilities Act mandates the protection of persons with disabilities by ensuring that the government, private sector and NGOs provide assistance in situations of risk and humanitarian emergency.<sup>24</sup> Nevertheless, opportunities for persons with disabilities to participate in disaster management are not given in current laws and regulations.

In the context of disaster management, responsibility falls to the National Disaster Management Agency, which was officially established on

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21 [Center for Excellence in Disaster Management and Humanitarian Assistance, \*Malaysia Disaster Management Reference Handbook\*, CFE-DM, June 2019.](#)

22 [United Nations Children's Fund, \*Children with Disability in Malaysia: Mapping policies, programmes, intervention and stakeholders\*, UNICEF Malaysia, May 2014.](#)

23 [United Nations Children's Fund, \*Formative Evaluation of UNICEF's #ThisAbility Flagship Initiative 2017–2019 in Malaysia\*, UNICEF Malaysia, November 2019.](#)

24 [United Nations Children's Fund, \*Children with Disability in Malaysia: Mapping policies, programmes, intervention and stakeholders\*, UNICEF Malaysia, May 2014.](#)



1 October 2015. Malaysia Civil Defence Forces has been appointed as the Secretary for Disaster Management Committee at the state and district levels and is responsible for enhancing community resilience to, and preparedness for, disaster.<sup>25</sup>

### **4.2.3 Research findings for Indonesia**

#### *4.2.3.1 OPDs' participation in the government's and international non-governmental organizations' non-COVID-19 response*

In terms of engaging with Gol and INGOs in the response to non-pandemic disaster, four OPDs confirmed their participation as tokenism participation, while the other three were in the upper category of Arnstein's ladder of citizen power participation.

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“Together with BPBD, in 2018, we contributed to the formation of the disaster resilient village [called] DESTANA. Out of 17 sub-districts in Karanganyar, we mapped the vulnerable spots, [then] we initiated DESTANA. The LIDI Unit [Disability service unit] is always involved as a facilitator.”

– A representative of OPD in Karanganyar, shared in the FGD

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The three OPDs whose experience reflects citizen power participation were engaged with the Gol at both national and local levels. Their engagement was very strong and showed significant outcomes. For example, at the planning stage, the Gol relied on their expertise and knowledge to map and address the needs of people with disabilities when carrying out a disaster-resilient village programme.<sup>26</sup> The Gol also engaged them to prepare accessible shelters for people with disabilities and vulnerable groups in 2021, during the Mount Merapi Eruption in Central Java, as stated by a representative of OPD1, “We were involved by the Provincial Disaster Management Agency or BPBD in designing shelters. We managed to ensure the Gol to build accessible shelters for vulnerable groups. The shelter was a special education school building where all the accessibility had been already in place.”

Another example of citizen power participation at the planning stage was when OPD2 took part in developing the National Master Plan for Disaster Management. Moreover, Gol, through the BNPB involved OPD3 to provide

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25 Center for Excellence in Disaster Management and Humanitarian Assistance, *Malaysia Disaster Management Reference Handbook*, CFE-DM, June 2019.

26 DESTANA stands for *Desa Tangguh Bencana*, which literally means “disaster-resilient village.” It is a project of the BNPB to increase the capacity of the villagers to prepare for and mitigate disaster risks.

input for disaster management policy development. “[We were] involved by the government in initiating the Disability Service Unit at provincial level. Then we were engaged in policymaking. We were involved, we contributed. We discussed with Zaenal (head of legal bureau of BNPB at that time), and colleagues of YAKKUM (it is a local NGO).”

Four OPDs ranked their experience at the lower level of participation,<sup>27</sup> which is tokenism. They said even though the Gol, through the BNPB or the Provincial Disaster Management Agency (BPBD), had invited them to provide input during policy consultation, this had not been taken into account. Afterward, they were no longer involved in the Gol decision-making process as stated by the representative of OPD4, “[Usually] the Government (BNPB) invited PPDI<sup>28</sup> (as the official umbrella for the OPDs), but now the Gol no longer invite them, instead, the Gol invites us most of the time.” A representative of OPD5 supported the evidence in her statement, “We were invited in the meeting to give information on the disability issue.”

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“I worked with UNOCHA to help them identifying relevant easy and accessible mechanism for cash assistance program (for people with disabilities),”

– representative of OPD2

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At the implementation stage, four OPDs experienced citizen power participation, when engaging with Gol and INGOs in humanitarian actions. The data showed that, in 2018, during earthquake and tsunami responses at Palu and Donggala, central Sulawesi, one of the OPDs was given an opportunity to play an important role to ensure that the OXFAM team carrying out inclusive responses. As a representative from OPD1 observed, “The OXFAM consortium for Palu Emergency consulted with OPD1 to ensure the disaster response was inclusive. For over six months [we] were involved to introduce [disability issues] to village officials to mainstream it in their response.” His statement was supported by another member of OPD1, who said, “We were assigned to Palu and Lombok for earthquake response. We were deployed to join the response team to the impacted areas.” In short, the deployment of the OPD in the emergency response had become regular practice. The OPD response team consists of trained people with disabilities, as mentioned by a representative of OPD1, “We have the trained and experienced team that can be deployed immediately in emergency. But it needs an emergency funds, [but] we don’t have it.”

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27 One OPD called OPDI3 or Institut Inklusi Indonesia was established in 2018. It takes a role in the OPD coalition in the COVID-19 response.

28 PPDI is the Indonesian Federation of People with Disabilities (*Persatuan Penyandang Disabilitas Indonesia*), the umbrella OPD in Indonesia.



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A boy using a wheelchair is pushed by his friend in a rural area in Indonesia. Both boys are smiling.

Feedback mechanisms include a hotline service and complaint box, which are not inclusive, supported with face-to-face meetings or meeting in person, to give feedback and complaints to relevant stakeholders.<sup>29</sup> If people with disabilities are not systematically invited to such meetings, this may negatively affect their opportunities to provide feedback to policymakers and relevant stakeholders in the whole disaster risk management process, as shared by the representative of OPD1, “We were seen as beneficiaries, as an object of the response programme. The feedback mechanism is not inclusive and unreachable for us. It was not polite to criticize the assistance given to us. If there was feedbacks or complaints, it was considered as personal preferences.”

Four OPDs said that they were climbing up from the ‘tokenism’ level of citizen participation to the highest level, citizen power, as a result of not only getting involved with GoI, but also with INGOs during humanitarian responses. The high frequency of disasters in Indonesia provides numerous opportunities for OPDs to engage with INGOs. They agreed that the INGOs had given them a big contribution to this achievement. The INGOs had equipped the OPDs with the capacity to enable them to participate actively in humanitarian issues, “In 2008,

29 Iwisara, Nancy G. and W. Setiabudi, *Accountability to Affected Population: In cash and voucher assistance in central Sulawesi and Lombok*, 2019.



ASB trained us on Disaster Reduction. Therefore in 2010, when Mount Merapi erupted, we could put our knowledge to our work. [It is] very useful [to have] knowledge,” said one of participants during the FGD. Another participant, a representative from OPD4, supported this statement in the interview, saying, “We were invited to the training facilitated by ASB.”

The participation of well-capacitated OPDs in disaster response was found to support humanitarian actors and the community to prepare more inclusive assistance and be able to reach groups at heightened risk, such as people with disabilities and the elderly.

#### *4.2.3.2 OPDs’ participation in the government’s and international non-governmental organizations’ COVID-19 response*

It was observed that the level of civic participation in response to the COVID-19 pandemic was different to that of other non-COVID-19 situations. Even though the Gol set up regulations to engage with OPDs, the engagement of the Gol with OPDs has not been as strong as it was in non-pandemic emergency responses. It was observed that it was most likely because OPDs were not seen to have the experience needed to participate in a response to the pandemic.

It was observed that the regulations mandating engagement with OPDs were not adhered to at the early stage of the response. None of the OPDs was given an opportunity to engage when COVID-19 task forces were established, either at the national or local level.

After the early response, Gol started to involve the OPDs, in line with laws and regulations to implement a response with a rights-based approach, piggybacking on the experiences of OPD engagement in non-COVID-19 disaster responses. The Gol initiated OPDs’ engagement, collecting input and feedback on disability inclusion, and relying on OPDs’ expertise for mapping and addressing the needs of people with disabilities. As a representative of a parent group stated, “In April 2020, the Women and Children Protection Ministry (KemenPPA) invited and asked us for inputs in developing the protocol for children with disabilities affected by COVID-19. We were included and we developed the protocol.” This statement aligns with that of a representative from OPD1, who said, “[We] developed the regulation together with the Women and Children Protection Ministry and COVID-19 task force. [We] made 2 protocols on children and women with disabilities.”

The advantage of OPDs collaborating for extensive periods during non-pandemic emergencies is that it resulted in the organic creation of an OPD alliance during the COVID-19 pandemic. When OPDs realized that they were not engaged in the early COVID-19 response, some of them jointly took action to assess the needs and challenges of people with disabilities during the COVID-19 pandemic. The director of OPD7, who is an active member of the



OPD alliance<sup>30</sup> on inclusive COVID-19 response, mentioned in the interview that, “In COVID-19 response context, there was initially no engagement of OPD except the initiative from OPDs alliance, so we initiated an assessment of the impact of the COVID-19 to people with disabilities. Later, [the assessment] will be followed up by deeper assessment in 2021.”

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“In COVID-19 response context, there was initially no engagement of OPD except the initiative from OPDs alliance, so we initiated an assessment of the impact of the COVID-19 to people with disabilities. Later, [the assessment] will be followed up by deeper assessment in 2021.”

– Director of OPD7

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The joint action to undertake assessment of the impact of the COVID-19 pandemic on people with disabilities drew the attention of the GoI. The evidence was used to advocate with the relevant ministry/ministries on the situation of people with disabilities. As stated by a representative of OPD7, “We then have taken the initiative to use data from the assessment for advocacy to the Ministry of Health and we were welcomed by Balitbang (research and development department). As a result, a budget allocation emerged in the village fund, for disabilities.”

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– Representative of OPD7

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There were instances in the COVID-19 response where other organizations allowed a platform for OPDs’ expertise and experiences in disability. OPDs could provide inputs and advocate the needs of people with disability, as said by representative of OPD1, “In consortium with [Humanist Institute for Development Cooperation] HIVOS,<sup>31</sup> Kapal Perempuan [a local NGO] and CISDI [Center for Indonesia’s Strategic Development Initiatives], we did identify the needs (of people with disability), advocated to community health center to

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30 The OPD alliance in responding to the challenges during COVID-19 pandemic is an informal alliance. It was formed by several activists from OPDs when they saw the challenges and the gaps in terms of addressing the disability issue in the government’s COVID-19 programme.

31 HIVOS is an INGO based in the Netherlands and currently works in 40 countries, including Indonesia.



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A young man who is blind and carrying a white cane is being led by another young man on a city street.

bring the health service closer to people with disability, raised the awareness of village officials.”

Disability issues are the responsibility of MoSA in the cluster system that Indonesia has. During the emergency response, issues related to disability are addressed only by MoSA. So far, the output of the cluster coordinated by MoSA in the COVID-19 response was around communication guidelines, and OPDs played a significant role in providing inputs on disability-inclusive communication. Their involvement in this implementation phase can be considered as citizen power, as illustrated in Figure 3.

The capacity of OPDs to engage in non-pandemic work, combined with national-level policies and regulations to engage OPDs, resulted in a mutual understanding and agreement between OPDs and the Gol on the non-negotiable need to work together during the COVID-19 pandemic.

#### 4.2.3.3 *OPD participation with UNICEF in humanitarian action and COVID-19 response*

Research data showed that UNICEF Indonesia worked with the OPDs through two mechanisms. First, through a third party, which were the Gol cluster system and NGO partnership and, second, through informal connections.

UNICEF's primary engagement with OPDs is through supporting reasonable accommodation and promoting disability inclusion through UNICEF's partners. UNICEF systematically promotes disability inclusion in the emergency clusters on protection and refugees, by encouraging the involvement of OPDs in the activities or programmes of the cluster. UNICEF uses this opportunity to engage with OPDs. As one representative of UNICEF said, "To encourage the OPDs to actively participate in disaster responses. We encourage and support the provision of [a] Sign Language Interpreter."

UNICEF also engages with OPDs through partnership with NGOs, such as Humanity & Inclusion (HI; formerly known as Handicap International), Plan, General Health Christian Foundation/General Health Christian Foundation Emergency Unit, MuslimAid, RedR and Wahana Inklusi Indonesia. When partnering with INGOs and NGOs, UNICEF also uses this opportunity to engage with OPDs. However, OPDs are often not aware that the GoI and the INGOs and/or local NGOs they work with are partners of UNICEF. As a representative from a parent group said, "We never work with UNICEF. We had a collaboration with HI in developing inclusive learning material for children with disability for learning from home."

The second mechanism UNICEF has to connect with OPDs is informal connections. For example, UNICEF engaged OPDs to design and decide the development of information, education and communication materials in the COVID-19 response.

In interviews, OPDs mentioned that the elements needed to meaningfully engage people with disabilities in emergency preparedness and response include the provision of reasonable accommodation and accessible materials. A representative of OPD3 stated in the FGD, "For the blind, it will be helpful if the softcopies were provided before, so we can read first [before the meeting]."<sup>1</sup> The provision of a sign language interpreter in meetings or workshops is also important, as it can help deaf participants to understand the topic and enable them to participate.

The OPDs also mentioned that a barrier to partnership with UNICEF was the high operational procedures standard that needs to be met. As the representative of OPD7 said, "The requirement to engage in the funding partnership, the OPD has to have several years experiences in managing funds. Something that we cannot have at the moment."

In regard to a reliable database of OPDs, the research found that UNICEF needs a structured database system of OPDs, rather than relying on informal connections. A member of UNICEF staff mentioned in the interview that, "In the early response, I seek [disability focal point] and [consultant on inclusive education] for [OPD] references." The existence of OPDs in the database is relevant to help staff when seeking potential partners.

## 4.2.4 Research findings for Malaysia

### 4.2.4.1 OPD participation in the government's and international non-governmental organizations' non-COVID-19 response

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“The Authorities should open their eyes in order to help persons with disabilities.”

– Member of Malaysia OPD

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None of the OPDs consulted in Malaysia had engaged with the authority in emergency response, until the COVID-19 pandemic hit the country. This is reflected in an observation from an NGO representative, who said, “We annually have floods in different states, but the (authority) does not think it is necessary to consult OPD. How can they (authority) support people with disabilities? The response was done by non-OPDs, perhaps they may be aware of the disability issue but it (the disaster response) was not inclusive.”

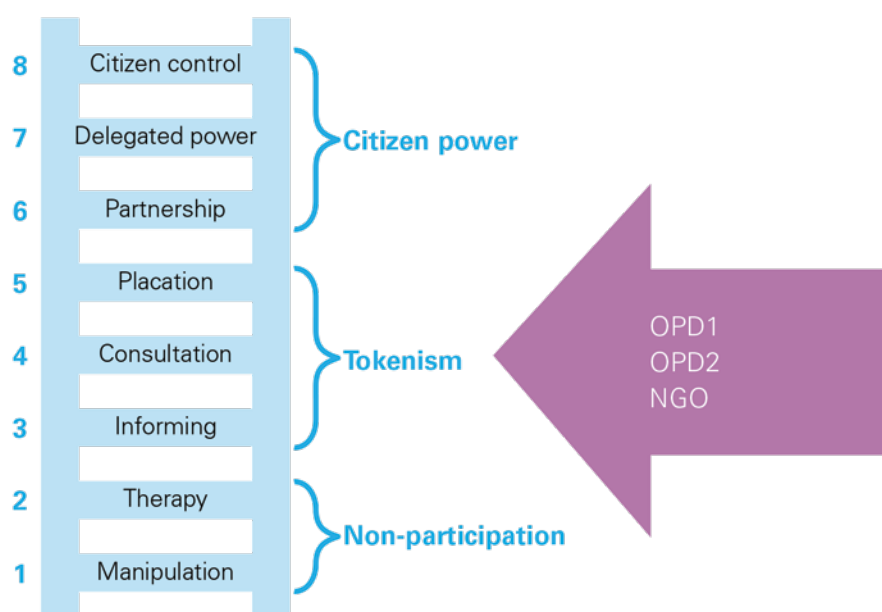
### 4.2.4.2 OPD participation in the government's and international non-governmental organizations' COVID-19 response

OPDs in Malaysia described having little opportunity to participate actively in the COVID-19 response, including at a coordination level. GoM assistance was distributed through the coordinating agency, as mentioned by a member of OPD5 in the FGD, “There was no coordination (with government) in the first few months (of the pandemic) [...] The coordination needs to be improved. The platform needs to be in place. Every assistance goes to the coordinating agency (before being distributed).” A representative from an NGO added, “Not much engagement between government relevant agency and OPDs, even with the National Council of Persons with Disabilities, because we didn't hear much action between that Council and the government agency.” To support this, a representative of OPD2 said, “I think our OPD is always being involved, we have been asked to participate in the budget consultation and being asked for our feedback, but it is up to them to accept or not our feedback.” Later, the GoM gave OPDs an opportunity to contribute more in the COVID-19 pandemic response by taking into consideration the feedback from individuals and OPDs. This was mentioned by a member of OPD2, who said, “After the feedback we gave to the government, sign language interpreter available on TV, (as well as) an infographic with audio explanation for the blind. The government provided meals programme to support people with disabilities.”

### 4.2.4.3 OPD participation with UNICEF in humanitarian action and COVID-19 response

With regard to UNICEF engagement with OPDs in humanitarian action, it has been observed that the level of participation that UNICEF has with OPDs is at the

**Figure 2.** Level of OPD participation with the GoM and INGOs in the COVID-19 response



level of ‘tokenism’. The research could not find mention of OPDs cooperating with UNICEF as part of their humanitarian action. Currently, UNICEF’s main partner in disability inclusion is a nationwide NGO with expertise in early intervention education, as well as mental health and psychosocial support for children with disabilities and their parents. While the OPD database contains specific information about the areas of expertise OPDs have on certain issues, many of the OPDs have a weak infrastructure, making it challenging for them to form sustainable partnerships.

The findings show that UNICEF has two mechanism to promote OPDs’ engagement. Firstly, through its partner and, secondly, through the provision of reasonable accommodations to ensure accessibility in UNICEF programme implementation. OPDs are invited to an accessible meeting room as a participant. A representative from OPD2 said, “So far, I can access, UNICEF provides enough accessibility but I have to check the [UNICEF] website as well.”

The findings show that efforts to engage OPDs have been made at UNICEF through the programme implemented by its partners and by the constant support from the program specialist (gender and disability) in the country office. UNICEF’s engagement with OPDs is facilitated by the programme specialist, who supports and maintains an open and equal relationship with them. A representative of OPD6 said in the FGD, “It is good to have an [prior] existing relationship, they [the



OPDs] need to be aware that you could reach out to them [the United Nations, the humanitarian agencies]. Organization like us do not have the contact [person]. We don't have the contact. I am lucky that I have worked with UNICEF and I know the person in touch." The programme specialist can play a role as a focal point for disability in the UNICEF office. A member of National Autism Malaysia said in the discussion, "It is good to have an existing relationship with UN but not every organization has that relation. They need someone you can reach to. A focal point."

Similar to Indonesia, OPDs in Malaysia find it challenging to partner with UNICEF due to the high number of requirements, including online training. The research showed that, although they understood that these requirements are obligatory in order to work with an international agency, not all OPDs have the capacity to meet them, particularly the online training. Experienced people were needed to assist them. A representative of an NGO said, "We know the UNICEF system quite well. We signed another programme document last year. The programme agreement is quite heavy in sense, many people were involved, [gone through] basic training. But I learned quite a lot working with the disability specialist, because it quite clear what was expected from us." Furthermore, she added, "The online trainings are accessible, since they are made to be accessible, but not sure how accessible the system is. But there is technical issue (in the online training) that made us difficult to complete. Some of us need to go through all over again. It needs stable internet traffic. It was quite frustrating for screen reader users, and for persons with intellectual disability if you work with them."

## **4.2.5 Conclusion and lessons learned**

### *4.2.5.1 Lessons learned*

These are the lessons learned from the OPDs' engagement in humanitarian action in Indonesia and Malaysia:

- Engagement of OPDs with governments and INGOs in humanitarian work is gradually growing. They are all climbing up the ladder of participation, from tokenism to the highest level, citizen power. This is because government and INGOs have engaged them in two ways; as disability and inclusion resources and as potential partners to be deployed in humanitarian responses. Therefore, they were equipped with the knowledge and skills to work on humanitarian issues.
- The OPDs who experience citizen power participation are visible for their expertise and skills, able to put humanitarian knowledge into practice and show a strong organizational culture.
- The willingness of UNICEF to engage with OPDs through partners and directly is an important starting point to improving visibility of OPDs.
- For many years, OPDs in Indonesia have been networking extensively during non-pandemic emergencies. This resulted in the organic creation of an OPD



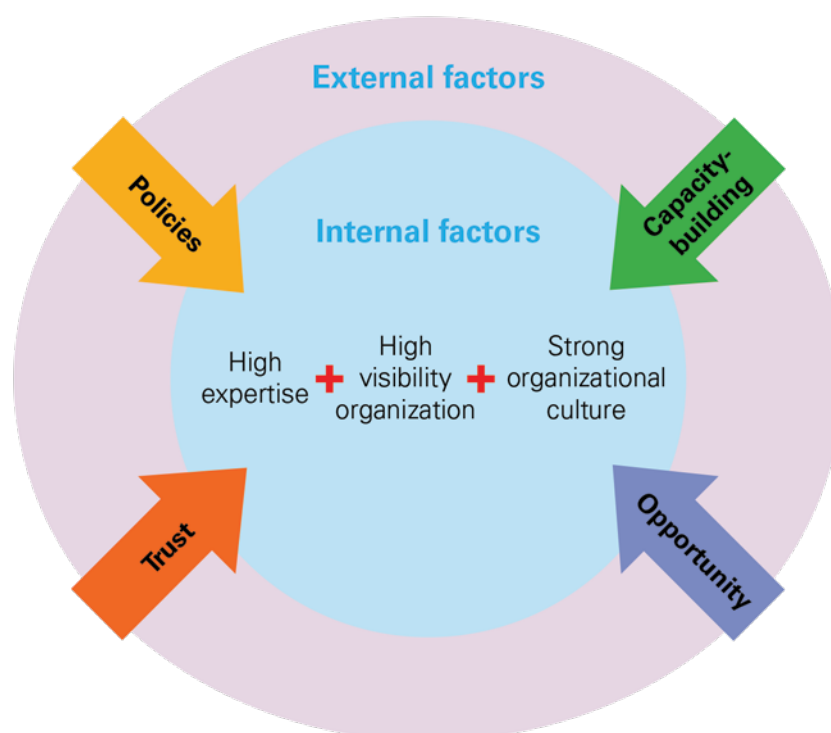
alliance during the COVID-19 pandemic. This alliance collected information that subsequently informed government policy development for the COVID-19 response. The initiative of the OPDs to set up a coalition helped to address the gaps.

- Individual representatives from OPDs – who were proactive and persistent – have advocated and provided feedback to government and other humanitarian actors, leading to a more disability-inclusive humanitarian response. Active participation in structured coordination meetings as well as using established bilateral channels of communication can affect changes in policies.
- The provision of reasonable accommodation and disability-accessible information is important to meaningful engagement in emergency response planning and implementation.
- The existence of a dedicated UNICEF disability expert allows both UNICEF and OPDs to more easily engage and work in partnership.

#### 4.2.5.2 Conclusion

As per Arnstein’s ladder of citizen participation, citizen power is closest to what is meant by meaningful engagement. With regards to OPDs, effective partnership and meaningful engagement of OPDs in humanitarian actions depend on internal and external factors.

**Figure 3.** Significant factors that facilitate OPDs reaching the citizen power level



The internal factors that influence effective partnership and meaningful engagement are when the OPDs show a combination of:

- High expertise: OPDs must have sufficient experience in conducting research, and in advocacy to influence regulation, policies and experiences in monitoring policy implementation;
- High organizational visibility: The more stakeholders can see OPDs' actions to represent rights-holders, the more likely it is that OPDs will be engaged in the partnership; visibility requires OPDs to be active in meetings or workshops with decision-makers or INGOs;
- Strong organizational culture: OPDs with strong leadership, a clear vision and mission, and capacitated human resources are more likely to be involved in the decision-making process.

The external factors that enable OPDs to experience citizen power participation are:

- Trust: This may be built through various meeting channels, where every party can contribute their expertise; humanitarian actors provide a space for OPD engagement and create opportunities for active participation;
- Capacity-building: Humanitarian actors equip OPDs with basic capacities for emergency response, through accessible information on specific topics such as child rights and humanitarian standards;
- Policies: Supportive regulations and laws to promote the meaningful participation of OPDs in every phase of emergency preparedness and response;
- Opportunity: Humanitarian actors providing a space for OPD engagement and creating opportunities for active participation.

The combination of these internal and external factors has enabled OPDs to engage in meaningful participation with humanitarian actors and policymakers, strengthening the inclusiveness and effectiveness of the emergency response.

#### **4.2.6 Challenges**

The research shows a great possibility to engage OPDs in emergency response. However, the following challenges were identified.

For policymakers:

- The concept of disability and inclusion can be perceived differently by authorities, presenting a barrier to opportunities and trust for the OPDs to participate.
- Local dynamics can hinder OPD participation, even where supportive national policies are in place. For example, in the decentralization system of Indonesia, local leaders may have different priorities in governing their areas,

with no guarantee that disability and inclusion is placed as a cross-cutting issue in their local planning documents. This can prevent budget allocation for OPDs to access provision for capacity-building or to deploy the emergency response team.

For OPDs:

- OPDs' experience in emergency preparedness and response may be limited. For example, in Indonesia and Malaysia, OPDs do not have strong experience in disaster management and therefore have limited visibility to government and other humanitarian actors.
- It is important to resource OPD participation. In Indonesia, some OPDs have well-trained emergency teams, but failed to deploy them due to budget shortage.
- Barriers to participation can be even more pronounced outside of capitals. In Indonesia, it was observed that there is a wide capacity gap between OPDs located in big developed cities and those located in remote areas.
- There is a need to strengthen representation of more marginalized groups, such as children and women with disabilities, and people with intellectual disabilities.

For UNICEF and other United Nations agencies:

- The lack of a dedicated focal point for disability inclusion can act as a barrier to engaging OPDs in meaningful participation in emergency preparedness and response
- There is a need to map OPDs so that humanitarian actors can identify and reach out to potential partners
- UNICEF standard operating procedures for partnership contain criteria (such as for accountability and auditing) that are difficult for local OPDs to meet.

### **4.3 Cambodia country case study: disability identification system informs Cambodian COVID-19 vaccination roll-out (sector: policy and public finance for children)**

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#### **4.3.1 Context**

When it comes to realizing the rights of children with disabilities, UNICEF Cambodia has established a fruitful collaboration with the Ministry of Social Affairs, Veterans and Youth (MoSVY), particularly its department of welfare for persons with disabilities.

UNICEF Cambodia collaborates with OPDs and national and international NGOs working on disability inclusion, particularly in the child protection sector. UNICEF and other development partners continue to advocate with their MoSVY partners on policy development and programme implementation in meaningful engagement with OPDs, which has resulted in MoSVY creating an extensive network of OPDs and other NGO partners to support programme delivery in the child protection and disability sectors.

In 2020, UNICEF supported MoSVY to develop the national disability identification system, with the aim of improving the collection of data on disability through governmental information systems, and the implementation of a social protection system that benefits people with disabilities and their families, such as disability-inclusive emergency cash transfers. The national identification system will also help improve access for persons with disabilities to care and employment opportunities. This identification system is framed within the rights-based approach to disability identification. The identification system has been developed in close collaboration with OPDs through consultative processes and by building on their inputs and lessons learned.

When the COVID-19 pandemic hit Cambodia, the collaboration between the Department of Welfare of Persons with Disabilities and OPDs was already in place, and the disability identification system was rolled out to 8 out of 25 provinces.

#### ***4.3.2 Partnership and engagement with OPDs in response planning***

People with disabilities in Cambodia have been recognized as a high-risk group and placed on the priority list for COVID-19 vaccinations, resulting from an effective advocacy from the Disability Action Council of Cambodia, OPDs, NGOs and the United Nations. To accelerate the vaccination of people with disabilities, MoSVY has built on the disability identification system already established in 8 of Cambodia's 25 provinces to improve the inclusion of persons with disabilities in the vaccine roll-out, through a mechanism of information sharing established between MoSVY and the Ministry of Health. Data extracted from the disability identification information system are sent to commune level, where confirmation of their consent to receive the vaccine will be sought from each person with a disability.

To inform people with disabilities of the benefits of vaccination and the accessibility of protocols, MoSVY, in collaboration with UNICEF and the Australia-Cambodia Cooperation for Equitable Sustainable Services programme, has produced a disability-accessible video spot, which includes sign language and captions. Radio spots will complement the awareness-raising material to remove barriers to information and communication for the majority of people with different types of disabilities.

In the 17 provinces where the disability identification system is not yet rolled out, the provincial Department of Social Affairs, Veterans and Youth Rehabilitation will rely on lists from self-help groups that are supported by NGOs and CSOs, including OPDs, to identify those eligible for priority vaccination. The OPDs and CSOs will provide additional support to facilitate access for persons with disabilities to registration and the vaccination itself.

#### ***4.3.3 Partnership and engagement with OPDs in implementation and monitoring***

The implementation of COVID-19 vaccinations for persons with disabilities started in June 2021. In the first week of the vaccine roll-out, 519 persons with disabilities were vaccinated in Phnom Penh under MoSVY's oversight. It is expected that the disability data list will not only facilitate the groundwork, but will also allow uptake of vaccinations and progress of roll-out for priority groups to be monitored. A network of 17 NGOs and OPDs (some of which manage the sub-networks of CSOs) have been engaged in the consultation process for the establishment of the disability identification mechanism, as well as roll-out of the vaccination.

#### ***4.3.4 Challenges and constraints***

Disability data are not yet collected systematically in all 25 provinces, and the risk is that people with disabilities who are eligible for priority vaccinations will not be informed. This is mitigated by engagement of the CSOs in 17 provinces working with persons with disabilities to support MoSVY in the implementation and monitoring of the vaccination roll-out.

#### ***4.3.5 Lessons learned***

Disability inclusion remains a key cross-cutting priority of UNICEF Cambodia's operations and results in the country programme plan.

Building on its mandate and strong collaboration with the Government of Cambodia, UNICEF was able to build the national system, while also promoting further government collaboration with OPDs in the design and delivery of the identification system, and in monitoring and evaluation. This was based on its mandate to advocate for vulnerable groups and to build the capacity of partners to identify vulnerable groups through development of mainstreamed and targeted programmes to realize the rights of all. The engagement of OPDs in the delivery of the identification system, as well as supporting cash transfer and social care programmes for persons with disabilities will have to be further strengthened within the development of the social protection framework, with the national system opening up to engagement and formal collaboration with the CSO sector in the delivery of social services.



## 4.4 Lao People's Democratic Republic country case study: identification of needs, adaptation of approaches and increasing access to and quality of services for children with disabilities in a participatory way (sector: child protection)

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### 4.4.1 Background information

UNICEF Lao People's Democratic Republic supported the Government of Lao People's Democratic Republic to implement a UNICEF Australia-funded project Strengthening Community-based Child Protection Services for Vulnerable Children (2017–2020) in two provinces: Xienkhouang Province in the north and Savannakhet Province in the south. Key implementing partners included the People's Supreme Prosecutor and the Ministry of Justice, and the Ministry of Labour and Social Welfare in partnership with the Ministry of Health and the Ministry of Education and Sports, as well as associations working with persons with disabilities, focusing on the care and protection of children in contact with the law, and children with disabilities.

### 4.4.2 Context

The Ministry of Labour and Social Welfare appointed an intersectoral team at the central level to provide support and monitoring of the project implementation, which comprised members of the departments for: older persons and persons with disabilities, Ministry of Labour and Social Welfare; the rehabilitation centre, Ministry of Health; inclusive education, Ministry of Education and Sport and representatives of the Association of Persons with Disabilities and the Aid Children with Disability Association. In addition, four mobile teams responsible for the care and support of children with disabilities were appointed in two target districts and two provinces of Xiengkhouang and Savannakhet. The teams conducted quarterly visits to the 18 target villages to provide health checks for children with disabilities and support and advice for parents of children with disabilities.

During the COVID-19 outbreak in Lao People's Democratic Republic, the existing multisectoral mobile teams continued to visit target villages to identify

needs and to sensitize village authorities and over 100 households with children with disabilities to COVID-19 prevention messages and make them aware of the available child protection services through WhatsApp and appropriate information, education and communication materials.

In addition, UNICEF supported the Ministry of Information, Culture and Tourism, and partners to develop 14 TV and radio spots, and public announcements on gender-based violence and prevention of sexual exploitation and abuse, child online protection and mental health and psychosocial support during COVID-19. These were developed in Laotian and two ethnic minority languages with sign language. These prevention messages reached 3.4 million people in 4,800 villages (50 per cent coverage) according to the Ministry of Information, Culture and Tourism estimate.

#### **4.4.3 Partnership and engagement with the OPDs**

To ensure that services meet the needs of children with disabilities and that the voices of children with disabilities are heard and considered in project implementation, the project involved and cooperated with the Secretariat of the National Committee for Persons with Disabilities and Organisations of Persons with Disabilities, the Association for Persons with Disabilities, the Aid Children With Disability Association and Association for Autism.

In addition, one person from the Association for Persons with Disabilities and one person from the Aid Children With Disability Association were invited to become members of the team that conducted the training for the local authorities, village coordinators and parents of children with disabilities in the target villages and districts. They also took part in monitoring of project implementation and the situations of children with disabilities in the target areas.

The project had involvement from and consulted with both the leaders and technical staff of the OPDs. The technical staff, who worked closely with community members and children, contributed and shared their experience and expertise on working with/for children with disabilities, while the supervisors played important roles on decision-making, planning, implementation and monitoring.

At grass-roots level, the 36 village coordinators (usually comprising one woman and one man per village, especially parents of children with disabilities) played important roles in:

- Visiting households with children with disabilities in their village on a regular basis to follow up and observe if parents were practicing basic rehabilitation exercises with children with disabilities, based on the suggestion provided by trainers/doctors, and sharing good practices to parents/families of children with disabilities



A boy with a disability receives support from a woman while seated at a desk studying at home.

- Collecting data on the well-being and needs of children with disabilities in their village and creating a file for each child, updating it on a regular basis
- Reporting to the village/district level for urgent cases of referral.

The OPDs remained involved from the project design phase throughout project implementation. This also included the period of implementation during the COVID-19 pandemic. The specific areas where they contributed to the project are:

- Development of training modules (e.g., case studies)
- Designing of the information, education and communication materials
- Planning and monitoring of project implementation
- Providing aid equipment, supportive and assistive devices to children with disabilities
- Training for local authorities, village coordinators and parents of children with disabilities
- Sharing and disseminating information about COVID-19 and how to protect children with disabilities from disease infection, during the COVID-19 outbreak.

#### **4.4.4 Challenges and constraints**

Financial capacity of OPDs is limited, with little financial support given by the government. It is insufficient to address the needs of children with disabilities and their families. External actors and donors have funded most of the low-cost family support service model. There is need to advocate at central governance level on budget allocation for child protection and for children with disabilities in particular.

Another challenge is the language and communication barrier. Most of the target villages are populated by ethnic minorities, and a substantive proportion of villagers have little access to education and cannot speak Laotian. This caused difficulties in communicating with the parents of children with disabilities, and reporting on their progress. To counter this, the village project coordinator will continue play an important role in supporting communication with the parents of children with disabilities. There is, therefore, a continuous need to build their capacity, especially in communication with children.

#### **4.4.5 Lessons learned**

Partnership and direct support from OPDs, especially as trainers for the project, helped to build trust with parents of children with disabilities, which was crucial to the project's success. Also, the representatives from the associations (who also have disabilities themselves, and are working with and for persons with disabilities) are well positioned to share their experiences during training and monitoring visits. They were seen as role models and inspiration for parents with children with disabilities to provide care and support for their children, and in being able to envision them as contributing to society in the future.

The project also led to the realization that the village coordinators played an instrumental role in data collection, regular monitoring and follow-ups of the project and that the provision of support and assistance to children with disabilities involves many sectors, including the OPDs who make a specific contribution in the area of mental health and psychosocial support.

### **4.5 Myanmar country case study: engagement of OPDs in the COVID-19 crisis in Myanmar (cross-sectoral: food/non-food items/communication/health)**

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### **4.5.1 Background information**

The NGO HI Myanmar partners with UNICEF on inclusive education and participates in humanitarian coordination forums such as the protection, child protection, health and WASH clusters.

In Myanmar, there is a disability inclusion working group in the inter-cluster coordination group. However, there is no formal participation of OPDs in the humanitarian coordination groups in the Humanitarian Country Team or inter-cluster coordination group. HI has advocated with the protection cluster the inclusion of OPDs in the coordination forum. Most of the OPDs have now started to become involved in the COVID-19 response.

### **4.5.2 Context**

HI conducted a situation analysis of persons with disabilities in the COVID-19 crisis. Data collection took place in May 2020, through telephone and face-to-face interviews covering 527 persons with disabilities. Of these, 14 per cent were children, 58 per cent were adults aged 18–59 years and 28 per cent were older persons aged over 60 years. The situation analysis also accommodated people with all types of impairment, with a 50:50 male to female ratio in the responses.

Immediate support needs of persons with disabilities were identified from the assessment findings and it was decided that assistance should be delivered in partnership with OPDs, considering their experience in working with people with disabilities. The OPDs that are partnered with HI are:

- Myanmar Physically Handicapped Association (MPHA) in Kachin and South East
- Myanmar Independent Living Initiatives (MILI) in Kachin
- Myitkyina Education for Blind (MEB) in Kachin.

Response priorities included: (1) awareness-raising on COVID-19 prevention; (2) distribution of food and non-food items including hygiene materials; (3) distribution of communication equipment (mobile phones, sim card, solar batteries); (4) safe rehabilitation services, reaching the most vulnerable persons with disabilities in target areas.

### **4.5.3 Partnership and engagement with the OPDs**

The specific roles that the OPDs played in COVID-19 response are as follows.

#### *4.5.3.1 In situational analysis and needs identification*

In addition to the general rapid analysis, OPDs conducted further analysis to identify the most vulnerable persons among those with disabilities in target areas. For example, an initial beneficiary assessment was done prior to distribution of food and non-food items to reach the most vulnerable group.



#### *4.5.3.2 In response planning*

Following identification of direct beneficiaries, HI and OPDs jointly discussed and identified the key response interventions, as well as their implementation modalities, available resources and possible linkages.

#### *4.5.3.3 In implementation*

With technical support from HI, OPDs worked very closely with the beneficiaries, by maintaining COVID-19 preventive measures in face-to-face visits or meetings. Necessary adaptations to activities were made to ensure that assistance was delivered in an inclusive and accessible manner. COVID-19 prevention messages were developed in a low-literacy format, translated into local languages and broadcast through radio. Door-to-door distribution of food and non-food items, as well as safe rehabilitation services, were provided to the most vulnerable group. Referral services were also supported by the OPDs (i.e., safe transportation, medications, etc.) for those in need of further health services and other specialized services.

#### *4.5.3.4 In monitoring*

OPDs also led monitoring of the effectiveness of assistance by measuring awareness and implementation of COVID-19 preventive measures; post-distribution monitoring for non-food items (NFIs); and follow-up on rehabilitation sessions through phone surveys using questionnaires developed by OPDs.

### **4.5.4 Challenges and constraints**

There are challenges and areas for improvement in engaging with OPDs.

- Limited human resource capacity and communication constrains OPDs' ability to take the lead on a situation analysis; HI had to revise the plan and deploy staff and camp-based volunteers
- Limited access to the internet for OPD members residing in villages impacted timely communication and exchange of information
- The OPDs were not using the same standard operational procedures as HI. One such challenge was related to managing beneficiary data following standard procedures including provided formats. The OPDs had limited knowledge of financial management, which was a key challenge to meeting the required standard on budget management. Similarly, the requirement of financial reporting in English was not easy for OPDs to comply with.

### **4.5.5 Lessons learned**

- Good communication, as well as an established network with government authorities and communities of people with disabilities are assets in gaining the trust of persons with disabilities.

- A significant advantage of collaborating with OPDs is that their representatives have strong knowledge and understanding of issues experienced by persons with disabilities, which allows programme design and implementation that is more in line with policies and strategies on disability inclusion. However, the NGO and United Nations partners should foresee providing guidance and building capacity in the areas of financial management, programme management and monitoring and evaluation.
- When a new programmatic approach is introduced by an NGO or the Humanitarian Country Team, they should support OPDs to fully understand the approach and to build their confidence before delivering the response activities to the target beneficiaries.
- Advocacy by OPDs on the situation of persons with disabilities that is supported by data will more likely result in an expanded scope of response and systematic disability-inclusive implementation during a crisis.

## 4.6 The Philippines country case study: supporting the caregivers of children with disabilities during COVID-19 (cross-sectoral with a focus on child protection and health)

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### 4.6.1 Context

During 2020 and 2021, the Philippines was severely impacted by the COVID-19 pandemic, experiencing over 1 million total cases out of a population of 108 million people (as of May 2021). To attempt to control the spread of the virus, the Government of the Philippines imposed strong lockdown measures, including stay at home orders, closure of schools and movement restrictions. With the closure of schools, medical facilities, habilitation and rehabilitation and other services, there was disruption in the provision of both mainstream and disability-specific services for children and people with disabilities. While children have not been as vulnerable

as adults to the direct health consequences of the virus, they have been acutely impacted by the interruption of essential government services and the protracted quarantine measures that have aggravated mental health and psychosocial risks for both caregivers and children.

UNICEF Philippines played a catalytic role in mounting a more child disability-inclusive COVID-19 response, taking on a crucial technical advisory and coordination role in the planning and implementation of relevant activities, while also leveraging its network across key sectors. This included, among other actions, the provision of mental health and psychosocial support to children, parents, adolescents and others, and supporting the government and civil society partners to deliver services to children.

Once the impact and the long-lasting nature of the pandemic became clear, UNICEF identified that its negative consequences were likely to be especially heightened for children and young people with disabilities. People experiencing social disadvantage and marginalization are known to be disproportionately impacted by ill health, while children with disabilities were also impacted by interruption of their normal routines and decreased access to therapy and other crucial services.

UNICEF also quickly realized that the ability of parents to provide a supportive, safe and nurturing home to children with disabilities would be jeopardized by the pandemic and ensuing containment measures. To ensure that the voices of children and people with disabilities and their families were heard, and that these voices would shape the COVID-19 response, UNICEF sought out forums and platforms to engage with OPDs and organizations of parents of children with disabilities.

#### **4.6.2 Partnership and engagement with OPDs**

##### *4.6.2.1 In situational analysis and needs identification*

After the onset of the COVID-19 pandemic, UNICEF took timely steps to engage with OPDs as part of the situation analysis and needs identification process. UNICEF advocated the activation and sustained engagement of the Council for the Welfare of Children Subcommittee on Children with Disabilities (the Subcommittee) to ensure a disability-inclusive response to COVID-19. To actively seek insights from children with disabilities and their families, in April 2020, UNICEF used a direct engagement strategy by supporting the design, roll-out and analysis of an online survey, *Situation of Children with Disabilities in the context of COVID-19*.<sup>32</sup> The survey included 6,561 responses from children with disabilities, or the parents of children with disabilities, and was

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32 United Nations Children's Fund, *Situation of Children with Disabilities in the Context of COVID-19: Results of a rapid online survey in the Philippines*, UNICEF Philippines, May 2021.



A family, including a boy in a wheelchair, are sitting outside their home in a rural village in Indonesia.

used to assess the situation of children with disabilities and their families during the unprecedented disruption caused by the COVID-19 pandemic and subsequent quarantine restrictions. Through the survey, UNICEF and the Subcommittee identified several needs of children with disabilities and their families, including lack of access to essential services, a decline in mental health, increased levels of violence in the home and the lack of accessibility of COVID-19 information.

#### 4.6.2.2 *In response planning*

Using the results of the above survey and ongoing engagement with OPDs and organizations of parents of children with disabilities through both the Subcommittee and other networks, UNICEF supported planning of a disability-inclusive COVID-19 response. UNICEF emphasized the need to be guided by the CRPD when designing interventions. In addition, UNICEF also consistently advocated the adoption of a twin-track approach to holistically address the needs of children with disabilities and their families. The first stream of the response thus consisted of promoting disability-inclusive mainstream interventions, such as ensuring the accessibility of crucial health materials. The second stream of the response focused on implementing disability-targeted interventions. The latter included the development and dissemination of disability-targeted social media messages for children with disabilities and their families, as well as the utilization of innovative approaches, such as



through remote platforms, to support the well-being of primary caregivers and families.<sup>33</sup>

Guided by the views of children with disabilities and their families through the survey and further direct engagement, and influenced by the desire to create a sustained intervention, UNICEF launched the six-part 'Caring for the Caregivers of Children with Disabilities' webinar series on 23 July 2020.<sup>34</sup> The series was prioritized because of the enormous burden on caregivers of children with disabilities during COVID-19, with the knowledge that the well-being of caregivers would greatly affect that of children with disabilities. The objectives of the series were to support the psychosocial well-being of primary caregivers of children with disabilities and their family members and to empower caregivers and families to better care for children with disabilities during the pandemic.

Topics covered during the webinar series, which was broadcasted on Zoom and Facebook (reaching 81,000 users through Facebook), included:

- The provision of mental health and psychosocial support to parents and caregivers
- Support for parents for providing mental health and psychosocial support to their children
- Empowering caregivers to better access services for children with disabilities during the pandemic.

To promote accessibility, sign language interpretation was available for the series.

UNICEF also provided technical assistance to the disaster risk reduction and management service of the Department of Education to develop 'Kakaiba-Yanihan! An inclusive psychosocial support for learners with disabilities'. The sessions were designed and continuously improved in consultation with a number of OPDs, service providers and parents of learners with disabilities, aiming to:

- Ensure the psychosocial well-being of learners with disabilities, including parents, teachers and caregivers during the COVID-19 pandemic
- Establish routines by conducting art-based and home-based activities with the assistance of parents, teachers and caregivers
- Build capacity of children, parents and teachers on child protection concepts and mechanisms to address issues and concerns affecting them during the pandemic

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33 [Disability-targeted social media messages drafted by UNICEF and disseminated through the social media pages of the Council for the Welfare of Children.](#)

34 [United Nations Children's Fund, 'Caring for the Caregivers of Children with Disabilities', webinar series, UNICEF, 2020.](#)

- Empower parents, teachers and caregivers with different approaches to support the learning process of children and to facilitate the safe return of learners and teachers to schools.

Online sessions served at least 383 learners with disabilities and their parents/primary caregivers. Versions of these sessions were later televised, thereby reaching a wider audience.

UNICEF also identified an important goal to catalyse a disability-inclusive response, leveraging partnerships with the government and organizations within the Subcommittee to sustain momentum towards achieving this goal throughout the response.

#### *4.6.2.3 In implementation and monitoring*

During the 'Caring for the Caregivers of Children with Disabilities' webinar series, UNICEF ensured the continued engagement of OPDs, organizations of parents of children with disabilities, and children with disabilities in a number of ways:

- Engagement with a network of OPDs to identify panellists and guests for the webinar series
- Engagement with a network of OPDs to increase awareness and viewership of the series
- Use of an ongoing process of engagement with guests and viewers of the webinar series, including OPDs and parents of children with disabilities, to identify future relevant topics to focus on as the webinar series unfolded. This ensured that the webinars were responsive to the actual needs of the target audience.

In addressing issues on information accessibility, including public health information, UNICEF partnered with the Filipino Sign Language Access Team and the Adaptive Technology for Rehabilitation Integration and Empowerment of the Visually Impaired to adapt the infection prevention and control training modules for persons with hearing and visual impairments, respectively. Team members of these organizations were themselves persons with disabilities, who actively provided services. In addition, UNICEF also supported engagement with members of the Philippine National Association of Sign Language Interpreters in the sustained provision of sign language interpretation to online events hosted by UNICEF and partners.

#### **4.6.3 Challenges and constraints**

- One of the challenges encountered was the difficulty in communicating during online meetings between the deaf community and hearing participants who were unfamiliar with sign language interpretation. This



required a third party to translate the sign language interpretation to the hearing members. The same challenge was encountered in the actual adaptation of the infection prevention and control training materials for people with hearing impairment that involved talents who are deaf. This led to a very slow and highly iterative process.

- There are dynamics and sensitivities to manage across OPDs, even within the same disability groups. Being cognizant of these dynamics and being familiar with the OPD ecosystem and how they relate to other stakeholders is crucial.
- Encouraging the Subcommittee to take a more structured and strategic approach to addressing the developmental needs of children with disabilities was a challenge. The already fragmented approach was exacerbated during the pandemic, adding challenges to implementing a disability-inclusive COVID-19 response.
- During design of the webinar series, there was an intention to invite guests from geographically isolated and disadvantaged areas. This proved difficult because of issues with accessibility and connectivity.
- There is an ongoing challenge in disaggregating data based by disability, which makes it more difficult to use broad-based survey approaches when identifying needs. There is insufficient coordination between national bodies, such as the Subcommittee and local government units. However, with the commitment by the Subcommittee to support activities for a year, a mapping of service providers at the local level will allow more efficient support for children with disabilities and their families.

#### **4.6.4 Lessons learned**

- Major drivers for success included the presence of an already existing coordinating body located within the government (i.e., the Subcommittee), its diverse representation from relevant national government agencies and CSOs, and support from the government through the Council for the Welfare of Children. The members of the Subcommittee had a wide OPD network that only needed 'synchronized' activation. This network was tapped into during the evidence generation exercise and was further targeted in subsequent initiatives.
- Owing to the nature of UNICEF's work (i.e., mainly through implementing and collaborating partners and provision of technical assistance to national government agencies), it was predictably difficult to have direct engagements with OPDs. Collaborations with strategically based CSOs, such as NORFIL and Physicians for Peace, were therefore crucial in initial and sustained engagement with OPDs. Subsequent bilateral engagements with OPDs sprang forth from the activities initiated during the COVID-19 response, including but not limited to work done with the Autism Society Philippines and Parent Advocates for Visually Impaired Children.
- On the other hand, the pandemic sped up the transition to greater utilization of remote platforms. This expanded the reach of interventions

(particularly the webinar series) and increased the scope and amount of interaction possible with OPDs and families of children with disabilities. The use of a webinar series bringing together OPDs and families of children with disabilities was an effective way to mitigate the loss of support groups, providing families and children with disabilities an opportunity to be heard. In addition, UNICEF has also been able to engage with OPDs that were previously not reached due to their physical remoteness, through the use of remote platforms. To optimize the use of online platforms, however, familiarity with accessibility features and how they can be tailored to accommodate the needs of persons with disabilities was necessary.

- The broader reach that was made possible through the use of a webinar format provided an opportunity to map support groups and establish a wider network for caregivers to reach out to when in need of support.
- UNICEF's brand, the cross-sectoral nature of its engagement with both government and CSO stakeholders, and the simultaneous streams of work both with partners and government expanded the reach of activities.
- As shown in the challenges in adapting the infection prevention and control training video to improve accessibility, there is a need to bridge the capacities of local OPDs with that of regional/international OPDs, which have the technical expertise to develop and adapt learning and communication materials.
- The role of parents and families cannot be overstated when engaging with children with disabilities. Organizations of parents of children with disabilities may therefore need to have equal recognition as OPDs.
- The experience of coordinating with government, OPDs and families of children with disabilities will prove valuable in the updating of the national strategic plan to make it more responsive to the needs of children with disabilities and their families in the context of COVID-19.

## 4.7 Annexes

### 4.7.1 Annex 1: Bibliography for the deep dive on Indonesia and Malaysia

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### 4.7.2 Annex 2: List of Informants

No.	Data collection tool	Female	Male	Total
1	KII – Indonesia	6	6	12
2	KII – Malaysia	4	4	8
3	FGD – Indonesia	5	6	11
4	FGD – Malaysia	5	3	8
5	Online survey	3	2	5
6	KII – UNICEF Indonesia	1	2	3
7	KII – UNICEF Malaysia	1	1	2
<b>TOTAL</b>		<b>25</b>	<b>24</b>	<b>49</b>



