Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action

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I. Introduction

Background

The adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006 was instrumental in marking a shift to a human rights-based approach to disability. Particularly since the World Humanitarian Summit (WHS) in 2016, there has been significant momentum on reflecting this approach in humanitarian action, and disability inclusion has gained growing prominence within the humanitarian system. 2016 marked the launch and wide endorsement of the Charter on Inclusion of Persons with Disabilities in Humanitarian Action, and various commitments being made by Charter endorsers. Additionally, at the 2018 Global Disability Summit, more than 81 commitments were made to further strengthen inclusion of persons with disabilities in humanitarian action. In 2019, the UN Disability Inclusion Strategy (UNDIS) was launched, applying across all pillars of work of the UN system, including in humanitarian contexts. Further, there is a growing body of guidance documents to support disability inclusive humanitarian action, including the Humanitarian Inclusion Standards for Older People and People with Disabilities; Guidance on Strengthening Disability Inclusion in Humanitarian Response Plans; and various guidance and other material produced by individual organizations.

Most recently, the Inter-Agency Standing Committee (IASC) Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (Guidelines) were developed by the IASC Task Team on Inclusion of

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1 See: [http://humanitariandisabilitycharter.org/](http://humanitariandisabilitycharter.org/)


4 The IASC is the primary mechanism for inter-agency coordination, policy development and decision-making that brings together 18 Principals of key UN and non-UN humanitarian entities. It supports its member organizations to deliver effective, principled and accountable humanitarian action that saves lives, protects and meets the needs of people affected by humanitarian crises. It advocates for the protection of rights of affected people and respect for international humanitarian law and the humanitarian principles of humanity, impartiality, neutrality, and independence. For more information on the IASC structure, working group and subsidiary bodies please refer to the IASC Website: [https://interagencystandingcommittee.org/](https://interagencystandingcommittee.org/)

5 The Guidelines were developed through a comprehensive and inclusive series of consultation processes with the contribution of over 600 stakeholders from the humanitarian and disability sectors. They set out essential actions that humanitarian actors must take in order to effectively respond to the risks faced by persons with disabilities and engage with them as partners in humanitarian response. See: [https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/launch-iasc-guidelines](https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/launch-iasc-guidelines)
Persons with Disabilities in Humanitarian Action and endorsed by the IASC in October 2019. The Guidelines complement and build on existing humanitarian standards, including the Core Humanitarian Standard, Sphere Handbook and companion standards including the Humanitarian Inclusion Standards for Older People and People with Disabilities. It is widely recognized that ongoing momentum is needed in order to sustain the gains made and further advance disability inclusive humanitarian action, for a real impact to be seen ‘on the ground’. For example, the 2019 workplan of IASC Results Group 2 on Accountability and Inclusion includes roll out of the Guidelines and support to the establishment of a Reference Group on Inclusion of Persons with Disabilities (Reference Group).

Purpose
The present document sets out the mandate, structure and working methods of the Reference Group during 2020, its first year of establishment. The Reference Group will be a platform fostering (resources permitting) long-term cooperation between UN, International Agencies, NGOs and organizations of persons with disabilities in promoting disability inclusive humanitarian response, including, but not limited to, supporting coordination on dissemination and implementation of key guidance materials, including the IASC Guidelines. The Group will build on and reinforce efforts of individual organizations in this regard; and links with broader processes for strengthening the quality and accountability of humanitarian action inclusive of persons with disabilities.

These terms of reference will be reviewed by Reference Group members and updated, as needed, on an annual basis (during quarter 1 of each calendar year).

II. Structure

Membership
Membership of the Reference Group is open to international, regional and local organizations of persons with disabilities (OPDs), non-governmental organizations (NGOs) and UN agencies, as well as interagency networks, multilateral or bilateral agencies, private sector, academics and others committed to promoting inclusion of persons with disabilities in humanitarian action. Donors, and/or governments may be invited as observers to provide technical input or to discuss certain relevant issues, when needed.

All members must agree to abide by and support human rights and humanitarian principles and standards; and are expected to actively contribute to the work of the Reference Group. A key activity of the Group during year 1 will be to establish agreed procedures related to membership, through open and transparent consultation. For example, the Reference Group may establish core and associate memberships as required to define levels of participation.

Individual members, regardless of membership levels, represent their organizations/ entities and have a role in informing and meaningfully engaging their respective organizations/ entities in relevant activities of the Reference Group. In order to advance the objectives of the Reference Group, Members are also

6 The IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action was established in 2016 with a 2-year mandate, to develop the IASC Guidelines. For more information on the Task Team, please refer to: https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action

7 As of mid-2019, the Task Team was absorbed into the IASC Results Group 2 on Accountability and Inclusion. For the detailed workplan of the IASC Reference Group 2 on Accountability and Inclusion: https://interagencystandingcommittee.org/results-group-2/documents/2019-priority-areas-work-iasc-results-group-2
encouraged, in coordination with the co-chairs, to share relevant information with networks and other coordination mechanisms that they participate in.

**Co-Chairs**

The work of the Reference Group will be facilitated through a tri-partite structure of co-chairs consisting of a UN Agency and an INGO active in humanitarian action, and the International Disability Alliance (IDA).

The co-chair positions of the UN Agency and the INGO will periodically rotate and be filled through open, transparent election processes. The selection of a new co-chair will be opened every 2 years, followed by expressions of interest and an established voting process. In order to facilitate regular turnover and smooth transition in the co-chair role, every effort will be made by acting co-chairs to encourage and support organizations expressing an interest in serving in the co-chair role.

The third co-chair position will be established as a permanent position and reserved initially for the International Disability Alliance (IDA), as the world’s largest membership organization of persons with disabilities that aims to represent the estimated one billion people with disabilities worldwide.

Commitment and responsibilities associated with the co-chair role rest with organizations, rather than individuals. For this reason, organizations, rather than individuals, are elected as co-chairs. Organizations volunteering for the co-chair role do so with an understanding that this role will require approximately 25% of the time of a full-time staff member. Time commitments likely will vary during certain periods. Further, the role of co-chairs in the Reference Group is to provide strategic direction, leadership and promote coordination. Thus, the interests of the Group, rather than the interests of the co-chairs’ own organizations, should guide the work of the co-chairs in their leadership role in the Reference Group.

A key activity of the Group during year 1 will be to establish agreed procedures relating to the co-chair function, through transparent consultation with members.

Specific co-Chairs responsibilities include:

- To coordinate and facilitate the activities of the Reference Group and ensure its effective functioning;
- To propose a work plan in consultation with Reference Group members, monitor its implementation and report on its progress
- To engage, consult and mobilize support from all stakeholders, with a particular focus on the constituencies and stakeholders they represent;
- To lead engagement with IASC Results Groups, IASC associated entities (including reference groups) and other humanitarian coordination mechanisms, including the cluster system, as

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8 For 2020, the voting process will be coordinated by the co-chairs of the former IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action, who will guide members through a transparent consultation process to agree on processes for formal election of co-chairs to the Reference Group, including criteria for nomination and voting procedures

9 IDA is currently the only existing organization representing roughly 1,100 OPDs from all regions and all types of disabilities. If any organization of persons with disabilities with similar membership composition in the future, the reference group may decide to amend the TOR to allow voting for this chair as well
relevant, to promote mainstreaming of disability inclusion across the humanitarian system and a coherent approach to integration of cross-cutting issues in humanitarian action;

- Convene and chair meetings/teleconferences of the Reference Group, and record, store and circulate records from meetings.
- During year 1 (2020), to establish a system for storing and disseminating information internally and externally, in consultation with Reference Group members;
- Particularly during year 1, to lead the development of working structures and procedures in consultation with Reference Group members, including but not limited to membership structure, arrangements for working groups, decision making processes, meeting procedures, budgeting and other administrative arrangements, as well as relationships with humanitarian coordination mechanisms;
- To support resource mobilization to reach the objectives of the Reference Group, including specific actions set out in the workplan and ongoing functioning of the Group;
- To represent the Reference Group externally, as needed, including in meetings and speaking engagements;
- To ensure that all materials, meetings and processes are developed utilizing universal design standards and reasonable accommodations and modifications are available on request.
- To ensure that all Reference group members are able to request and receive the disability accommodations they require for full participation in all Resource Group activities and functions

III. Activities

The Reference Group brings together key stakeholders for coordinated efforts on promoting inclusion of persons with disabilities in humanitarian action, building on the advances made through endorsement of the Guidelines. This includes, but is not limited to:

- Facilitating the printing, dissemination and language translations of the Guidelines in accessible formats;
- Developing an advocacy and communication strategy on the Guidelines;
- Support to the application/integration of the Guidelines into broader humanitarian policy, standards, guidance and tools;
- Support to individual organizations to integrate the Guidelines into their institutional policies and procedures; including through the various mechanisms of the UNDIS in the case of UN agencies;
- Facilitating the sharing of experience among humanitarian and disability actors on Guidelines implementation and disability inclusive humanitarian action more broadly;
- Developing tools and resources, supplementing the Guidelines, to support inclusive humanitarian action and disseminating these to relevant actors;
- Promoting and supporting on-going capacity building on inclusive humanitarian action, aligned with the Guidelines;
- Engaging with humanitarian coordination mechanisms, including IASC Results Groups, IASC associated entities, clusters and other structures, to provide support on disability inclusive humanitarian action, based on the Guidelines, as well as support the integration of other relevant aspects promoted by the IASC into disability inclusive programming;
• Promoting the generation, dissemination and use of evidence on the situation of persons with disabilities in humanitarian contexts and disability inclusive programming in humanitarian action;

• During year 1 (2020), establishing agreed procedures related to functioning of the Reference Group, including in relation to membership; working groups; decision-making; election of co-chairs; meeting and communication arrangements; disability accommodations; and relationships with humanitarian coordination structures;

• Particularly during year 1 (2020), and on an ongoing basis, promote broad participation in the Reference Group, including from non-traditional actors on disability inclusive humanitarian action;

• Any other activities that will contribute to disability inclusive humanitarian action

The Reference Group will develop a workplan for each calendar year, through a consultative process with all members. The workplan will include activities, timelines and sharing of responsibilities for joint efforts on promoting disability inclusive humanitarian action, as well as resource implications. Donor support will be vital to enable achievement of deliverables set out in the workplan.

Where relevant to advance implementation of the workplan, working groups may be established to focus on specific areas of work. Arrangements for the functioning of working groups will be established during year 1 (2020), through consultation with Reference Group members.

IV. Communication Mechanisms
It is essential to maintain regular communication (a) among Reference Group members and (b) between the Reference Group Members and their organizations/entities. The Reference Group will also maintain channels of communication with wider humanitarian and disability sectors, such as through the establishment of an online platform or other mechanisms.

All communication mechanisms will be provided in accessible formats, utilizing both universal design standards and specific accommodations and modifications as needed.

The co-chairs will be responsible for maintaining a system to store and disseminate information among Reference Group members and for ensuring regular teleconferences to monitor the implementation of the annual work plan. Additional online discussions about specific topics will also be timetabled throughout the year. Such calls may be initiated by the co-chairs and/or those leading thematic projects. Members will receive regular email communications related to the mandate and activities of the Reference Group.

Where feasible, in-person meetings will be arranged to enable more focused planning and monitoring of Reference Group activities and to facilitate closer coordination between Reference Group members and between the Reference Group and other humanitarian entities.

The present document is entering into force on the 22 January 2020.