

Terms of Reference for the United Nations' Stakeholder Group of Persons with Disabilities

The space for persons with disabilities in the United Nations

Processes and Procedures Document

The Stakeholder Group of Persons with Disabilities for Sustainable Development (SD) is the focal point for UNDESA, ECOSOC and the GA for all UN Sustainable Development policies. The scope of the Stakeholder Group of Persons with Disabilities for SD responsibility covers the Rio+20 outcome (including the 2030 Agenda, Sustainable Development Goals, High-level Political Forum, Financing for Sustainable Development, at global and regional policy processes of the United Nations. In addition, Stakeholder Group of Persons with Disabilities for Sustainable Development aims to cooperate closely with other constituencies linked to other UN policy processes. The Stakeholder Group of Persons with Disabilities is a recognized other stakeholder group within the UN and as such part of the Major Groups and other Stakeholder Coordination Mechanism.

History:

Original agreed by:

1st of March 2017

Section 1. Framework

1.1 Preamble

The Stakeholder Group of Persons with Disabilities was formally recognized within paragraph 43 of the Outcome Document the 'Future We Want' at the 2012 United Nations Conference on Sustainable Development held in Rio de Janeiro¹. Member States subsequently decided upon the modalities of stakeholder participation, and within the UN General Assembly Resolution A/RES/67/290 Member States specifically invited persons with disabilities *“to autonomously establish and maintain effective coordination mechanisms for participation in the high-level political forum and for actions derived from that participation at the global, regional and national levels, in a way that ensures effective, broad and balanced participation by region and by type of organization.”*²

Under the leadership of the International Disability Alliance and with the support of the International Disability and Development Consortium, coordinated inputs from persons with disabilities were provided to sustainable development processes, demonstrating a high level of engagement with intergovernmental processes at the UN.

The Stakeholder Group of Persons with Disabilities aims to enhance the opportunity for persons with disabilities, their representative organizations, and non-governmental and other organizations working on the rights of persons with disabilities to advocate with a unified voice for their inclusion in all sustainable development related UN processes. The present document provides guidance on how to be involved and also seeks to guarantee the sustainability of the active participation and inclusion of member organizations, strengthening their role and collaboration.

1.2 Name

The name of this informal network of persons with disabilities, organizations of persons with disabilities and their allies, governed by the present statutes referred to within the Processes and Procedures Document is the Stakeholder Group of Persons with Disabilities, herein after referred to as SGPWD.

1.3 Vision

The SGPWD envisions a world, where human rights are upheld, in particular those within the UN Convention on the Rights of Persons with Disabilities, and where disability-inclusive sustainable development is achieved. In this vision, persons with disabilities, their families and organisations meaningfully participate in all decision-making processes regarding sustainable development. This includes the planning, design, implementation, monitoring, review and evaluation of sustainable development policies at all levels– local, national, regional and international.

¹ UN General Assembly Resolution A/RES/66/288 entitled: The Future We Want, http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/66/288&Lang=E

² Paragraph 16, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N12/496/00/PDF/N1249600.pdf?OpenElement>

1.4 Mission

Our mission, as a self-organized space, is to ensure the effective coordination of the participation of persons with disabilities in United Nations processes related to sustainable development and other processes.

As a non-denominational and a politically neutral entity, it strives to ensure diversity and inclusion of all persons with disabilities, taking into account all impairment groups and diversity within region, sex, age, organizational type, and other marginalized groups within the disability community.

The SGPWD is intended to ensure the right to participation of all persons with disabilities in decision-making processes as mandated in CRPD Article 4.3³, 32.1 (a)⁴ & 33.3⁵ and to bring to life the disability community's principle of, "nothing about us without us."

1.5 Mandate

The SGPWD is recognized by the UN General Assembly Resolutions A/Res/67/290, as well as ad hoc agreements within different UN bodies and conferences.

The SGPWD facilitates the representation of persons with disabilities and officials within the UN system, whilst ensuring persons with disabilities are afforded the right to attend and intervene in official meetings, have access and avenues to submit information and documents, make recommendations, and organize events and meetings.

The Stakeholder Group of Persons with Disabilities:

Provides:

1. Platforms (online and offline) to foster dialogue among persons with disabilities, other stakeholders and partners, on issues and/or decisions that affect or are relevant for persons with disabilities.
2. Spaces for persons with disabilities to agree on joint statements and policy positions for UN processes

Conducts:

1. Capacity-building and empowerment for persons with disabilities so that they can take part in and be informed of UN processes.
2. Training of persons with disabilities on practical skills for effective participation, networking, influencing, lobbying at all levels.
3. Work on developing policy positions in an open, transparent, inclusive and democratic manner.

Coordinates:

1. The logistics of persons with disabilities' participation in UN processes.

³ 4.3 In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

⁴ 32.1 (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

⁵ 33.3 Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

2. Inputs into UN processes where the UN requires civil society participation through the major groups and other stakeholders.
3. Resources allocated by the UN, which are offered to civil society to enabling their participation in processes.

1.6 Guiding values and principles

The purpose of the SGPWD shall be to ensure the advancement of the human rights and the inclusion of persons with disabilities within sustainable development. The SGPWD shall, in particular, ground its advocacy in a human rights-based approach (HRBA), thus the standards within the UN Convention on the Rights of Persons with Disabilities (and other UN treaties) guides the 2030 Agenda for Sustainable Development and other relevant non-binding frameworks and instruments.

The SGPWD is based on the following principles:

- a) To respect the sovereignty of all its members and recognize their expertise on issues affecting their own constituency;
- b) To promote the participation of persons with disabilities in all sustainable development related processes;
- c) To follow democratic governance ensuring transparency, accountability, open and full consultation;
- d) To promote inclusiveness, respect, solidarity and equal treatment of all disability constituencies in all regions of the world;
- e) To fully respect in all of its work non-discrimination on any grounds including (but not limited to) disability, race, gender, religion, age, language, ethnic origin, and sexual orientation, and to promote inclusiveness, respect, solidarity and equal treatment, including reasonable accommodation.
- f) To ensure the leadership of persons with disabilities, including through their representative organizations;
- g) To be independent of external control and to carry out its work with a voluntary in nature; and
- h) To be committed to fostering outcomes, which are equally relevant to all persons with disabilities, irrespective of type of impairment and special attention will be paid to those in the most challenging circumstances or situations.

Section 2. Membership and participation

2.1 Membership and participation

Membership of the SGPWD is open to all persons with disabilities, organizations of persons with disabilities, non-governmental and other organizations working on the rights of persons with disabilities, and non-governmental donors working within this space. All members must sign up online or in person agreeing to the vision, mandate, values and principles set out above.

2.2. Becoming a member of the Stakeholder Group of Persons with Disabilities

Individuals or organizations register through an online form and all must adhere to the present statutes called the Processes and Procedures document.

Based on the information provided, members are automatically signed up for the general mailing lists as well as of the Working Groups relating to their area/s of interest. A starter kit welcoming new members to the SGPWD is sent to their listed email address. This kit contains general information and an introduction to the work and structure of the

Stakeholder Group and a link to the website. All members must be registered in at least one Working Group of the Stakeholder Group of Persons with Disabilities and may participate in as many as they wish.

2.3 Ending Participation

Membership may be terminated when an individual or a member organization has undertaken actions unlawful, illegal or in contravention of the above values and principles, that are likely to threaten or compromise the name, reputation or assets of the SGPWD. Such actions will be investigated by an ad hoc Committee - set up by the Permanent or Alternate Representative - which will present an unanimously agreed proposal to the General Assembly. The member organization will have the right of appeal to the General Assembly. Appeals must be lodged within 30 days of the mailing of notification of the General Assembly's decision. If the appeal is lodged, the individual's or organization's exclusion will be suspended until the General Assembly finalizes a decision.

2.3 Rights of Participants

Participants of the Stakeholder Group of Persons with Disabilities have the right to:

- a) Nominate themselves or others to take part in meetings at the UN on behalf of the SGPWD;
- b) Submit inputs into the policy development of the SGPWD;
- c) Take part in activities of the SGPWD;
- d) Be fully informed of the work and activities of the SGPWD in a timely manner;
- e) Raise concerns or suggestions and receive a timely and appropriate response to their input;
- f) Propose initiatives for the SGPWD.

2.5 Obligations of Participants

Stakeholder Group of Persons with Disabilities' participants have the obligation to:

- a) Be registered in one or more working groups of SGPWD;
- b) Keep the SGPWD informed of their current contact details and, for organizations, information about their representative;
- c) Uphold the Guiding Values and Principles of the SGPWD and act in accordance with the Processes and Procedures document;
- d) In accordance with their interests and capacity, take part in the work of the SGPWD;
- e) Consult with the Focal Points prior to engaging in activities that implicate the SGPWD.

Section 3. Working Structure and Roles

3.1 Key Structures

The organizational structure is comprised of:

- a) Participants: will include either individuals or representatives of organizations
- b) General Assembly: will be composed of all participants, the Permanent and Alternate Representative and Focal Points
- c) Elected Representatives: will constitute one elected Permanent Representative and one elected Alternate Representative who shall serve for a two-year term. The two representatives shall preside over the General

Assembly, officially represent, guide and support the work of the SGPWD, and liaise between the SGPWD and relevant UN bodies

- d) Council of Working Groups: will be composed of the Permanent Representative and/or Alternate Representative and the Focal Point(s) of each Working Group. The Council of Working Groups will meet on a monthly basis to coordinate activities, messaging, policy development and coherence, and to define short term strategies
- e) Working Groups: will cover each of the UN processes which involve the SGPWD (external Working Groups) or support the internal work and/or policy coherence of the SGPWD (internal Working Groups)
- f) Focal Points: will be nominated for external and internal Working Groups, and will be the lead individuals that facilitate and coordinate the work of their respective Working Groups
- g) Regional Focal Points: will be appointed by external Working Groups if they deem regional focal points important to the development of policy positions and/or statements.

3.1.1 General Assembly

The General Assembly is the chief authority of the SGPWD. Comprised of all the participants, meetings are held once a year, either online, or online and in-person. The General Assembly may convene additional meetings whenever necessary, at the unanimous request of the Permanent and Alternate Representative. The Permanent or the Alternate Representatives shall chair all meetings, and notify the members of any meetings at least four weeks in advance, including within their notification a proposed agenda. Focal Points are expected to attend and to report to their constituencies. Decisions shall be passed when at least 50% of members are present and adequate notification of the meeting has been given. All decisions must be recorded and archived. Once a decision has been reached, this becomes the position of the SGPWD and will be upheld by the Permanent and Alternate Representatives.

The General Assembly has the following responsibilities to:

- a) Provide strategic direction and guidance
- b) Receive reports on activities and any policy or statements that have been delivered
- c) Review annual plan of the group
- d) Coordinate any future policies and resolve any issues where there may be overlap or conflict between Working Groups
- e) Make overall decisions by a simple majority
- f) Elect the Permanent and the Alternate Representative.

3.1.2 Permanent Representative

The Permanent Representative is the main representative of the SGPWD in the Major Group and other Stakeholders Coordination Mechanism. The core responsibilities of the Permanent Representative include:

1. To facilitate the public representation of the SGPWD and to provide strategic direction and guidance to the General Assembly.
2. To promote and coordinate the active participation of members in national, regional and global meetings related to sustainable development, and to conduct advocacy meetings in New York and regional meetings on behalf of the SGPWD.
3. To ensure coherence and synergies between the Working Groups within the Council of Working Groups.

Within the facilitation role, the Permanent Representatives shall:

- a) Organize the General Assembly's calls for the SGPWD;
- b) Ensure the effective functioning of Working Groups through the Council of Working Groups;

- c) Take active steps to support individual Working Groups that encounter challenges in fulfilling the responsibilities within the Processes and Procedures document;
- d) Take active steps to ensure that the Alternate Permanent Representative and Focal Points are fulfilling their tasks;
- e) Facilitate the activities of the SGPWD to maximize the Group's presence and participation within UN sustainable development-related processes;
- f) Ensure a record of contributions are archived (lobby points, statements etc.);
- g) Ensure that activities are regularly evaluated and assessed; and
- h) Delegate specific tasks to members.

Within the Governance role, the Permanent Representatives shall:

- a) Ensure the SGPWD adheres to the tenets of the CRPD and the Processes and Procedures document;
- b) Provide guidance for working structures;
- c) Determine the appropriate allocation of funding made available, in line with the SGPWD Guiding Values;
- d) Coordinate and facilitate the continuation and hand-over of the Permanent Representative position.

Within the Outreach role, the Permanent Representative shall:

- a) Conduct outreach to potential and current members;
- b) Promote effective preparation and participation of persons with disabilities in UN sustainable development processes;
- c) Provide regular updates of activities to members;
- d) Actively seek resources to enable a more balanced participation, especially those in the challenging circumstances or situations.
- e) Disseminate relevant data and information to members of SGPWD.

3.1.3 Alternate representative

The Permanent and the Alternate representatives aim to work closely to design, plan, implement and monitor the activities of the SGPWD. In the absence of the Permanent Representative, the Alternate representative will carry out the same activities as listed in 3.1.2.

3.1.4 Focal points

The Focal Points will carry out the technical facilitation of the Working Groups, organize meetings, as well as maintain official records of meetings, lists of participants, and action steps. Each Working Group will be headed by 2 Focal Points, preferably at least one based in New York or Geneva with familiarity with the UN. The Focal Points will ensure that the Working Groups adhere to the text of the CRPD, the 2030 Agenda and other key documents. In the case of conflicting opinions regarding priorities affecting different sectors of the disability community, all attempts will be made to resolve the conflict in a way that is amicable and satisfactory to all.

3.1.5 Regional Focal Points

The SGPWD, as an overall space, does not currently have regional or geographical Focal Points. However, the SGPWD may decide to establish such Focal Points at a later date.

3.1.6 Division of Labour

Permanent and Alternate Representatives will work in unison. Individual organizations will not be permitted to speak on behalf of the Stakeholder Group of Persons with Disabilities, unless requested by the Permanent and/or Alternate

Representatives or the General Assembly.

Division of labor will be decided by Permanent and Alternate Representatives.

The Permanent and Alternate Representatives must maintain minutes from their meetings, which will be made available to the entire Stakeholder Group of Persons with Disabilities.

Each Permanent and Alternate Representative must be from an organization, but can work as a team within their respective organizations.

Permanent and Alternate Representatives will be responsible for:

1. Coordinating as a team;
2. Providing assistance and support to Focal Points in the Council of Working Groups as well as on a bilateral request;
3. Preserving institutional memory.

3.2 Working Groups

The substantial work of the SGPWD will be carried out in Working Groups. Internal Working Groups - coordinated by Focal Points - will be responsible for strengthening the SGPWD ability to implement its vision, mission, and mandate. External Working Groups - coordinated by Focal Points, represented by the Permanent and Alternate Representatives - will participate in UN meetings and events, liaise with respective UN agencies, and coordinate inputs into policy positions and statements. Working Groups will make decision by consensus. If consensus is not reached, the Permanent and the Alternate Representative may intervene. The Permanent and Alternate Representatives or the General Assembly may decide whether to form a new Working Group or close an existing Working Group.

3.2.1 Internal Working Groups

Current Internal Working Groups in relation to the High-level Political Forum include:

- Working Group A: Drafting of the official submission on behalf of the SGPWD.
- Working Group B: Drafting position papers on sub-themes in line with SDGs goals under review;
- Working Group C: Planning and organizing side events
- Working Group D: Organization of Bilateral Meetings
- Working Group E: Accessibility at the HLPPF
- Working Group F: Communication
- Working Group G: Voluntary National Reviews

Responsibilities of the Internal Working Groups include:

- a. Electing Focal Points in line with the mandates detailed in 3.1.4.
- b. Development of a work plan and timeline, attending meetings, internally communicating, responding to any questions received, writing introduction for new members, and uploading documents such as statements and

policies to the website / internal library.

- c. Permitting the Permanent and Alternate Representative to resolve any issues or to fill the roles of Focal Points as needed.

3.2.3 External working group

Current External Working Groups Include:

- Working Group D: Science, Information and Technology Event
- Working group E: Data/SDG indicators.
- Working Group H: Financing for Development

Section 4. Election Process

An election process will take place to fill the positions of the Permanent and Alternate Representative roles as well as for the roles of the Speakers, who will represent the SGPWD in global and regional UN processes. Focal Points of Working Groups will be elected by the members of the respective Working Groups.

4.1 Steering Committee

A Steering Committee will be established. An open call to participate in the Steering Committee will be issued in a timely manner to the members of the SGPWD. All members of the Steering Committee who are representatives from organizations of persons with disabilities must come from organizations with clear governance structures, consultative processes, and meaningful accountability mechanisms towards the public and/or their membership.

The Steering Committee composition must meet the following criteria:

- a. 50% + 1 members must be representatives of organizations of persons with disabilities
- b. Equal representation of disability constituencies, including under-represented and emergent groups, and referencing Article 1 of the CRPD⁶
- c. Rural and remote representation
- d. Regional balance
- e. Gender balance

The Steering Committee's responsibilities include:

- a) Reviewing nominations received and submit their ranking for candidates through a secure and accessible online survey platform;
- b) During a call, Steering Committee members will discuss their choices and will aim to agree on a final decision.

⁶ Article 1. The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

4.2 Nomination Process

An open, transparent, inclusive and accessible nomination process will be launched, which will include components following the most recent UN requirements. The Permanent and Alternate Representatives must identify as a person with a disability. Speakers, who represent the SGPWD in various of UN processes, must fulfill criteria / requirements outlined by the UN and priority should be given to persons with disabilities.

Section 5. Decision Making Process

5.1 Policy

The SGPWD policies are aligned with the UN CRPD and the 2030 Agenda. The policies follow the overall guidance of its General Assembly, which receives specific policy recommendations from the Working Groups. All specific policies must be deliberated via the respective mailing list of each Working Group and synergies will be created within the Council of Working Groups. The General Assembly may discuss issues on policy where it understands that there is overlap and/or conflict, to ensure that there is coherence in the Stakeholder Group of Persons with Disabilities.

The process to create policy may vary from each Working Group, but must adhere to the following general rules:

1. A request for submissions is sent out, giving substantial time for everyone to contribute.
2. A Working Group call decides on a drafting group which should be a diverse representation of the Working Group's members.
3. The drafting group takes the submissions and any relevant previous policies, and drafts the policy in an open online accessible document
4. The draft is sent to all members via the mailing list for comments and suggestions.
5. The drafting group incorporates comments and suggestions and finalizes the draft.
6. The final version is sent around for further comments and red flags. Red flags should be only used by members if they cannot agree with the policy and are only valid if the members: 1) indicate what exactly they are objecting to 2) offer alternative wording and 3) provide contact details for the drafting group to contact them.
7. The drafting group meets to resolve any red flags in consultation with the red flag raiser.
8. Any unresolved red flags mean that the particular section must be removed from a policy or statement of the MGCY.

5.2 Statements

Statements are drafted by the Working Group members and those selected to speak. They must take the agreed SGPWD policy and reflect the relevant elements of that policy in any statement. Where there is no previous agreed policy or overall consensus within the SGPWD, then any statement must make this clear.

Statements must be written in an open, transparent and accessible document and circulated in due time to the relevant Working Group to allow for red flags to be raised when a statement does not follow agreed policy. It is the Permanent and Alternate Representative's role to ensure that statements are coherent with the SGPWD and that speakers adhere to agreed statements.

Section 6. Communications

6.1 External Communications

The SGPWD will have a Communication Working Group, which facilitates external communications. The Communication Working Group will manage the Social Media account and Press Contacts. Any message that is posted should relate to agreed Stakeholder Group of Persons with Disabilities' positions and statements. All external communication should go through Permanent and Alternate Representative and the relevant Focal Points on specific issues.

Section 7. Procedures

7.1 Entering into force on the 1st of March 2017.

7.2 Amending the Terms of Reference

The Process and Procedures Document can be amended but requires a decision of the General Assembly by simple majority and the set-up of a Renewal Group to draft the amendments. Final decision will be taken by the General Assembly.