***TECHNICAL MEETING***

***GLOBAL REPORT ON SITUATION AND RIGHTS OF PERSONS WITH DEAFBLINDNESS***

***GENEVA 13th September 2017***

***Concept note and provisional agenda***

***Background***

With the adoption of the Agenda 2030, attention has been paid to leaving no one behind. Persons with disabilities through intensive advocacy have succeeded to break their invisibility in the MDGs to be included in the Sustainable Development Goals. However, persons with disabilities are not a homogenous group and some constituencies such as persons with deafblindness are very often much more marginalised.

The multiple barriers that they faced such as lack of access to support services, accessible information and assistive devices makes it very difficult to even structure themselves in strong advocacy group to voice their issues. They are often marginalised even within the disability movement and can’t do not get a chance to engage in political participation and public life to claim their rights.

Experiences of WFDB and IDA in the 10 years of work on the implementation and monitoring of the Convention on the Rights of Persons with Disabilities have shown that there is very little attention paid by national and International stakeholders on the issues of persons with deafblindness. This is both the results and the cause of the general lack of knowledge of the diversity of issues and specific inclusion requirements of persons acquired or congenital deafblindness.

While there is a fairly organised community of services providers gathered within deafblind international, it did not manage to connect with the broader disability movement. Issues of persons with deafblindness are indeed tackled by a set of very specialised stakeholders. WFDB as well as its members such as the African deaf blind union have succeeded progressively to engage with the broader disability movement to amplify their message within IDA as well as EDF or more recently African Disability Forum or Sense international within the IDDC.

Few elements show that even among the disability specific work persons with deafblindness are marginalised. There are only 7 reference to persons with deafblindness in the 2011 world report on disability, 10 times more references to persons who are deaf or persons who are blind. There have been only 6 specific references to persons with deafblindness in the CRPD concluding observation of 40 countries review up to December 2016 (20 times less than for deaf persons or blind persons).

To raise the profile of issues of persons with deafblindness, there is a critical need of an evidence based global report on situation and rights of persons with deafblindeness that would become both a reference for CRPD and SDGs implementation. Such report would also be WFDB contribution to the 2020 SDGs baseline. It is planned to produce a follow up report in 2025 to measure progress.

Such reference global report is critical to build common ground and understanding across regional and global disability, development and human rights stakeholders. WFBD will use to process of development of the report to mobilise both WFDN members, their allies as well as the UN agencies. The process will be fully consultative, including via a survey, to ensure strong ownership by WFDB members.

The report will be built on evidence gathered by researchers of the International Center for Evidence in Disability London School of Hygiene and Tropical Medecine (ICED-LSHTM). While the focus of data collection by WFDB and partners will be on lower income countries, the European conference of Deafblind international in September 2017 will provide a great overview of situation in higher income countries.

As a key milestone in the development of the global report, an expert meeting will also be organized in September in Geneva both to mobilize and to gather contribution of different NGOs and UN agencies including WHO, OHCHR, ILO and the Special Rapporteur on the rights of persons with disabilities among others.

***Meeting participants***

* Board members (asia, latin America, Europe, Asia, Africa) of WFDB
* Sense international
* IDA
* IDDC
* Academia
* UN agencies

***Provisional Agenda***

09.00-09.30 Opening and Introduction

09.30-10h30 Who are persons with deafblindness (definition, life cycle data issues, diversity of support)?

11.00-12.30 Key findings on persons with deafblindness ‘s outcomes enjoyment of rights

14.00-15.30 Challenges and good practices for inclusion of persons with deafblindess

16.00-17.30 Opportunities and strategies to build a momentum for inclusion of persons with deafblindness.

***Provisional structure of the Global Report***

The content of the report will be framed both by the CRPD and SDGs. It will combine source of information ranging from disaggregated national censuses and surveys, literature review, national report to the CRPD committee, good practices documentation from Sense International as well as feedback and information from WFDB members.

Part 1: Who are persons with deafblindness?

* 1. Diversity of persons with deafblindness:
  2. Diversity of support required

Part 2: Situation and rights of persons with deafblindness

2.1 Education

2.2 Health

2.3 Employment

2.4 Home and family

2.5 Equal recognition before the law

2.6 Habilitation and rehabilitation

2.7 Social protection

2.8 Living independently and being included in the community

2.9 Violence and access to justice

2.10 Public life and political participation

Part 3: Way forward

3.1 Key issues to consider

* Increasing awareness
* Law & policy considerations
* Scale up support system, including costs of inclusion / exclusion
* Remove barriers
* Voice, self-advocacy, and inclusion in decision-making
  1. Recommendations and call for action