Input to the Report of the Special Rapporteur on Protection of Internally Displaced Persons with Disabilities

Light for the World | 14 February 2020

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# A) About this Submission

The Special Rapporteur on the Human Rights of Internally Displaced Persons is calling for inputs from development organizations and all other stakeholders, to the preparation of her upcoming thematic report to the Human Rights Council on the protection of internally displaced persons with disabilities.

Section B provides selected answers by Light for the World to the questionnaire outlined in the call for input.

Light for the World is a global disability and development organisation, breaking down barriers to enrich society and unlock the potential in all of us. Our global headquarter is in Austria and we have Country Offices in Burkina Faso, Ethiopia, Mozambique and South Sudan. Our vision is an inclusive society for all where no one is left behind. We enable eye health services and empower people with disabilities in some of the poorest regions of the world.

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# B) Input to the Upcoming Report of the Special Rapporteur

The following answers draw from the experience of Light for the World in the Republic of South Sudan. Light for the World supports development projects in South Sudan since 2002, maintains a country presence since 2012 and works with IDPs in various settings..

Persons in situation of internal displacement, regardless of the phase or setting of displacement, are referred to as IDPs throughout the submission. Persons with disabilities throughout the submission are understood to include women and men, girls and boys with disabilities. Gender-specific statements are marked accordingly.

## Q1 Provide existing data and evidence on persons with disabilities in situations of internal displacement (globally or in a specific region or country) and/or challenges and gaps with regards to the collection, analysis and use thereof.

According to a 2018 Factsheet by H&I and IOM, a total of 1.742 million persons with and without disabilities, are displaced in host communities, collective centres, POC sites, and other camp-like settings across South Sudan. If the rate of persons with disabilities is at least equal to the WHO global estimate of 15%, there would be around 260.000 IDPs with disabilities in South Sudan (Annex I).

According to a 2020 Factsheet by UNHCR of the Don Bosco Collective IDP Site in Juba, South Sudan, 26% of all vulnerable households have at least one member with a disability. Overall, only around 2.5% of the IDPs have a disability. 65% of the persons with disabilities identified are women and girls with disabilities. (Annex II)

A 2014 assessment of the Mahad IDP Camp conducted by Light for the World indicates that 2.4% of the IDPs at the site had a disability, 50% of those female (See Annex III).

A 2018 assessment of the Mangaten I and II IDP Camps with a total of around 15000 residents resulted in an identification of 129 (57 males; 72 females) persons with disability were identified in Mangaten I IDP Camp and 138 (75 males; 62 females) PWDs identified in Mangaten II IDP camp as at the time of this report. The age range was 1-80+ years. In camp I, nineteen percent (19%) are children aged 1-17 and in Camp II twenty three percent (23%) are children aged 1-17. Most of the identified IDPs with disabilities have visual impairment followed by physical impairment, four (4) are totally blind two from each camp and eight (8) with epilepsy 5 in camp I and 3 in Camp II respectively (See Annex IV).

The discrepancy of the 15% global estimate of persons with disabilities and the percentage of IDPs with disabilities indicates that identification of IDPs with disabilities is incomplete. Due to stigmatisation of persons with disabilities, lack of access of IDPs with disabilities to camp management structures and unawareness of statistical tools such as the Washington Group of Questions, persons with disabilities are undercounted.

A 2017 report by Human Rights Watch additionally indicates that not all persons with disabilities were able to flee violence and access IDP camps, which might additionally explain the underrepresentation of IDPs with disabilities. (Annex V)

## Q2. Share reports about the experiences of IDPs with disabilities during the various phases of displacement and in different settings, including their support needs and forms of discrimination or violence experienced as relevant, and any information that includes a gender and intersectional analysis.

In April 2014, Light for the World conducted a disability inclusion assessment of the IDP camp Mahad (see Annex III). In April 2018, Light for the World conducted a disability inclusion assessment of the Mangaten IDP Camps I and II, hosting over 15000 IDPs at that time (see Annex IV). Basis for the assessment was a simple service-oriented checklist (see Annex VI)

The results of both assessments were very similar. While there are some differences among IDP camps in South Sudan, specifically related to the camp management and previous disability mainstreaming interventions, the issues observed are representative of the overall situation of IDPs with disabilities in South Sudan.

Persons with disabilities and their families are located at long walking distance from essential services like health centres, water points and bathing areas. This limits their access to these services or renders them unavailable in the first place.

Shelters, including cooking areas are not physically accessible and lack comfortable sleeping arrangements for persons with physical disabilities, such as but not limited to padded sleeping mats and raised beds. IDPs with disabilities report that the camp is congested, with small, old tents that are flooded whenever it rains.

Toilets, bathrooms and water points are not physically accessible to persons with disabilities. There is no system in place for provision of assistance to unaccompanied individuals with disabilities and elderly persons unable to fetch their own water. The toilets lack seats, rendering their use difficult and uncomfortable for persons with physical disabilities unable to squat.

Toilets and bathrooms do not provide privacy and security for women and girls with disabilities. The lack of seats of toilets particularly affects women and girls with disabilities.

Food distribution points in both camps are physically not easily accessible to persons with disabilities, and there is no provision for transporting food to their shelter. However, IDPs with disabilities are most times supported by friends or neighbours to deliver their food ration to them in their accommodations. Those that cannot prepare their food may receive assistance from neighbours or community workers. Food may not be easy to eat and digest for children with developmental disabilities and the elderly, and there is no supplementary feeding for these groups of people since there are only three agencies providing support in these camps and only one is supporting malnourished children.

There are no organisations providing necessary assistive devices and mobility aids to persons with disabilities.

Health information is in principle but not comprehensively accessible. Health services are far from accommodation, and there is no transport or other arrangement to assist persons with disabilities to access such services. Health workers, however, are not trained or sensitised on disability and accessible communication methods. Children with epilepsy are unable to access treatment and medication. Furthermore, physical rehabilitation services are not or rarely available in the camp.

In Madad IDP Camp, there was a primary school and a child-friendly space. Neither was accessible for children with disabilities. Lacking chairs, children with physical disabilities found it uncomfortable to sit on the floor. None of the volunteer teachers in the school had any knowledge on inclusion of children with disabilities in the classrooms. There was no early childhood intervention programme for identification of children with disabilities, and no adaptive learning materials for children with disabilities.

## Q3. Describe the relevant national, regional and/or international legal and policy frameworks applicable to IDPs with disabilities, as well as achievements and challenges in their implementation.

The Republic of South Sudan has neither signed the UN Convention on the Right of Persons with Disabilities (UNCRPD) nor the Charta on Inclusion of Persons with Disabilities in Humanitarian Aid.

The official launch of the National Disability and Inclusion Policy took place at the end of 2016. It does not specifically mention IDPs. Its implementation on the ground is hampered by lack of funding, awareness and capacities.

Considering the humanitarian setting, most sectors rely heavily on international donor support, which is mainly channelled to humanitarian response. In the aftermath of the December 2013 to April 2014 open conflict in South Sudan, Light for the World carried out an informal random appraisal of the accessibility of humanitarian services provided by various agencies in Mahad and Gumbo IDP camps and the host communities.

This random appraisal primarily targeted provision of education and rehabilitation services for children and adults with disabilities, general physical accessibility of the IDPs camps and knowledge, attitude and practices on disabilities of staff of various organizations providing humanitarian assistance.

It was found out that the knowledge, competencies, vulnerability and the needs of persons with disabilities especially children, girls and women were being ignored

Majority of the staff were not aware of the need for accessible facilities, and those contracted to construct facilities for IDPs were not only unaware of IDPs with disabilities but also lacked skills on accessible built environments.

In most of the programmes and services provided in the camps and host communities, there were no deliberate attempts by the relevant organizations or the government to mainstream the needs for persons with disabilities in the project design.

There were two main reasons for this. On the one hand, disability mainstreaming was seen as complicated and expensive process by majority of the staff who were not aware of what it entails. On the other hand, there was lack of internal capacity among humanitarian agencies to deliver disability-inclusive responses.

Disabled People's Organizations (DPOs) were not adequately involved in the whole humanitarian response framework as key stakeholders.

## Q4. Provide concrete examples of good practices and challenges in addressing the protection and support needs of IDPs with disabilities, providing them with inclusive and accessible humanitarian assistance during displacement and supporting the achievement of durable solutions.

In 2015, Light for the World conducted a sensitisation and awareness workshop with international NGOs active in humanitarian aid sector. The workshop indicated a lack of methods and guidance to implement the concept of inclusion. Consequently, Light for the World started a pilot on disability Mainstreaming in Humanitarian Response.

Light for the World identified DICD (Disability Inclusion in Community Development) as a good method for disability mainstreaming. Light for the World developed practical DICD activities in IDP camps in Juba on basis of experiences of coordinating DICD services with the Sudan Evangelical Mission in Mundri. Persons with disabilities were identified during a disability audit, registered, and later received medical attention.

In general, the Light for the World’s concept of DICD in IDP camps proceeds in two phases. In short-term service provision, persons with disabilities are rehabilitated, later discharged and the next from the waiting list get services. In long-term service provision, children very young or with severe disabilities are visited twice a week. Children who are visually impaired, deaf and hard of hearing are visited once a week. People with Epilepsy and people who gets assistive devices are visited once a month. In the IDP camp Mahad, most of the clients that Light for the World started to rehabilitate were later discharged as the relatives start taking care of the persons with disabilities.

DICD activities were hampered by conflicts among IDPs in the camp. To mitigate these, Light for the World manages an inclusive sports project. In addition to addressing ethnic tensions, this activity also raises awareness of disability inclusion by fostering exchange between IDPs with and without disabilities, particularly children. The sports activities are also used as a tool to engage with girls and boys with disability on topics related to health and violence prevention.

Additionally, there were tensions between IDPs with disabilities and IDPs without disabilities resulting from a perceived better treatment of the former group, for instance related to food distribution. Awareness-raising activities among the general IDP population have significantly decreased these tensions, as described in the latest Light for the World activity report on its IDP work (see Annex VII)

A result of the DICD activities are that participants with disabilities in the project become ambassadors of inclusion and peaceful coexistence, carrying out security patrols, assisting other persons with disabilities, volunteering in child-friendly spaces or acting as after-school tutors. In turn, IDPs without disabilities also engage more with their peers, fur instance by taking children of other families to school.

## Q5. Describe efforts undertaken to ensure the active coordination, participation and meaningful consultation with internally displaced persons with disabilities and their organisations in decisions affecting them during all phases of displacement. Information about the outcomes achieved and the remaining gaps would also be welcome.

The national DPO Federation’s constitution is accepted by government. DPOs took over responsibilities within the Disability Working Group which is chaired by the Ministry of Gender, Child and Social Welfare of South Sudan. UNHCR and ICRC promote inclusion of persons with disabilities in internally displaced person’s camps, especially regarding education in emergency.

To increase autonomy and independence of persons with disabilities in line with the CRPD, Light for the World supports DPOs to build communication, advocacy and leadership capacities, and to have structured associations and a national level federation. The national DPO Federation unites different ethnic groups and thus is a successful paradigm for peaceful coexistence. In 2019, at least 10 DPO members received training from Light for the World to become inclusion facilitators in inclusive humanitarian aid sensitization of UN bodies and international NGOs.

Consultancy on disability mainstreaming led to a current 4-year programme by Dorcas, Edukans and Light for the World targeted on inclusive vocational education and training. Oxfam includes 5% of budget for inclusion in every proposal related to Humanitarian aid in South Sudan. World Vision has assessed 1.300 persons with disabilities that benefit from their food distribution services.

During first steps of implementing DICD in IDP camps in cooperation with UNHCR and other agencies, Light for the World was supported by two persons from the Association of the Deaf to conduct inclusive education in child-friendly spaces in the IDP camp Mahad. Furthermore, one member of the Union of the Physically Disabled as well as one from Union of the Blind have been supported by Light for the World to conduct awareness raising activities and training activities of camp managers and leaders in IDP camp Mahad.

## Q6. Describe how the support needs of IDPs with disabilities have been taken into account in relevant humanitarian and development planning, including to ensure the effective management and dissemination of accessible information at all stages.

Based on the learnings from DICD in IDP camps, Light for the World supports camp management teams and humanitarian agencies to make humanitarian response disability inclusive. The training activities are based on an extensive repository of capacity-building and awareness-raising material (see Annex VIII)

Following suggestions from Light for the World, the IDP Camp Mahad Management added one person with a disability to the management team. The candidate received training on leadership and governance by UNHCR and the governmental Relief and Rehabilitation Commission of South Sudan. Additionally, the candidate attended trainings on disability inclusion and disability management by Light for the World. This intervention noticeably increased disability inclusion in the camp’s services.

Based on the learnings from DICD in IDP camps, Light for the World further started a pilot programme to mainstream disability in Humanitarian Response with three components. First, implementation of DICD approach in IDP camps. Second, disability mainstreaming in humanitarian response training & coaching together with UNFPA, World Vision, Oxfam, ICRC and others. Third, DPO strengthening through capacity building and development of a national DPO Federation.

To support a UNMISS training on self-defence and road safety for girls, Light for the World hired a sign language interpreter so that deaf and hard-of-hearing girls could participate on an equal basis in the training.

Light for the World supported the UNFPA Sexual and Reproductive Health Unit on disability inclusion in their annual strategy. In 2016, Light for the World trained 25 UNFPA-supported nurses and midwifes from local clinics on disability mainstreaming.

Evaluation of the activities is positive, but monitoring and evaluation, access to data and sustainability of inclusion in a sector of high staff turnover remain an issue.

Knowledge and skills of humanitarian agencies and public authorities on disability mainstreaming have increased after training. Participants are provided with necessary instruments, resources and network through the involvement of DPOs. The next step is individual strategic planning of organizations with coaching by Light for the World. To transfer skills into policies and practices, the involvement of relevant decision-makers is crucial.

It is challenging to monitor and evaluate impact of disability mainstreaming training and coaching of mainstream humanitarian stakeholders. Consequently, client organizations are advised to include the Washington Group Questionnaire into their assessments to collect data of service provision to persons with disabilities.

## Q7. Describe actions considered or planned for 2020 to provide IDPs with disabilities with inclusive and accessible humanitarian assistance during displacement, to promote durable solutions and to foster their active participation and meaningful consultation in decisions affecting them during all phases of displacement.

In 2020, Light for the World will continue its regular project activities as described for instance in paragraphs 35, 36, 39, 40 and 43.