**10 November 2017**

**Lumos comment on the Committee on the Rights of Persons with Disabilities Draft General Comment on Equality and Non-discrimination (Article 5)**

**Introduction**

Lumos welcomes the initiative by the Committee on the Rights of Persons with Disabilitiesto develop the General Comment on Equality and Non-discrimination, and subsequently the opportunity to provide comments.

Lumos is an international children’s charity, founded by author J.K. Rowling, working to end the institutionalisation of children around the world by 2050. Lumos supports governments and communities to transform education, health and social care systems for children and their families, helping children move from institutions to families and family-based alternatives in the community.[[1]](#footnote-1)

In this submission, Lumos has provided suggestions to amendment certain paragraphs relating specifically to achieving equality and non-discrimination through deinstitutionalisation.

Sentences and words marked yellow indicate suggested additions to the text.

**Suggested amendments to Paragraph 1:**

With this General Comment, the Committee on the Rights of Persons with Disabilities (the Committee) aims to guide State parties and other stakeholders, and to clarify the obligations of States parties in relation to non-discrimination and equality as enshrined in article 5 of the Convention. The Committee considers that guidance in this regard is necessary as in carrying out its mandate, it continuously bears witness to discriminatory treatment of persons based only on actual or perceived disability that impairs or nullifies the enjoyment of the rights of persons with disabilities and those associated with them. Having completed more than 60 constructive dialogues with States parties to the Convention representing all regions of the world, the Committee is concerned that discrimination of persons with disabilities persists. The Committee routinely observes discrimination which includes: violations to the right to access the built environment, transportation, information and communications on an equal basis with others; negative portrayals of disability in the media and harmful stereotypes; deprivation of the right to legal capacity; institutionalization of persons with disabilities, including children; curtailments in access to justice, education, employment and to the right to participate in cultural life, recreation, leisure and sport, to name but a few examples.

**Suggested additional Paragraph to** **part VI General obligation of States parties under the Convention relating to non-discrimination and equality:**

The realization of equality and non-discrimination requires State parties to create and implement deinstitutionalization policies. ‘Institutions’ can vary in name, size and structure, however there are several defining elements that prevail in institutional care, including the lack of choice and control a person has over day to day decisions, rigidity of routine, isolation from community life and disproportion in the number of persons with disabilities living in the same environment.[[2]](#footnote-2) It is therefore necessary that States:

1. Implement comprehensive deinstitutionalisation policies that include preventing institutionalisation, creating and strengthening new services and support for individuals and families in the community, closing institutions, improving housing, promoting inclusive education, undertaking behavior change programmes to challenge attitudes in society;
2. Replace institutionalized settings with independent living support services;
3. Ensure public or private funds are not spent on maintaining or establishing new institutions.

**Suggested amendments to Paragraph 43:**

The principle of the ‘best interests of the child’ is rarely applied to children with disabilities. Many children with disabilities do not have access, on an equal basis with others, to education, housing, or goods and services. General laws concerning childhood rarely consider children with disabilities. When designing and implementing anti-discrimination and equality measures under article 5, States parties should consider the situation of children with disabilities into account. In particular, States parties should address violence and institutionalization of children with disabilities as a matter of discrimination. State parties should implement deinstitutionalization strategies which support children to live with their families, or in alternative family care in the community. States parties should also adopt age-appropriate support measures to enable all children with disabilities to exercise their right to be heard, in all procedures that affect them, including in parliament, committees and bodies of political decision-making.[[3]](#footnote-3) States parties should, in the appropriate cases, foster the provision of or promotion of accessible means, modes and formats of communication to facilitate non-discrimination and equality rights of children with disabilities.

**Suggested amendments to Paragraph 64:**

Article 19 of the Convention reaffirms non-discrimination and recognition of the equal right of persons with disabilities to live independently in the community. In order for the right to live independently and be included in the community to be realized, state parties have to take effective and appropriate

measures to facilitate the full enjoyment of the right and the full inclusion and participation of persons with disabilities in the community. This involves ensuring deinstitutionalization strategies are implemented, and in accordance with the Committee’s General Comment on article 19, resources are allocated for independent living support services, accessible and affordable housing, support services for family carers, and access to inclusive education.

**Suggested amendments to Paragraph 74:**

Data collection and analysis are important measures to monitor anti-discrimination policy and laws. State parties should collect and analyse data, disaggregated by, *inter alia*: sex, age, ethnicity, type of impairment, socioeconomic status, gender identity, sexual orientation, religion, language. State parties must take into consideration that many persons and children with disabilities live outside households and ensure that they are included in data collection. The data collected should be broad and cover statistics, as well as narratives and other forms of data. Design, collection and analysis of data should be participatory, i.e., undertaken in close and meaningful consultation with organizations of persons with disabilities. Data should give information on all forms of discrimination.

**For further information or questions please contact:**

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1. To read more about the scale of institutionalisation globally, see Lumos’ factsheet on the global picture: <http://wearelumos.org/content/children-institutions-global-picture>. For more information about the harm of institutionalisation to children download Lumos’ Risk factsheet: <http://wearelumos.org/content/children-institutions-risks>. [↑](#footnote-ref-1)
2. Committee on the Rights of Persons with Disabilities’ General Comment No.5 (2017), Living independently and being included in the community, Article 19. [↑](#footnote-ref-2)
3. Committee on the rights of the child, General Comment No. 9 (2006), The rights of children with disabilities, Article 12 - Respect for the views of the child. [↑](#footnote-ref-3)