**Draft General Comment No. 5 (2017)**

**Article 19: Living independently and being included in the community**

**Submitting organization**

**FIADOWN** – Federación Iberoamericana de Síndrome Down, conformed by 19 organisations (Asociación Síndrome de Down de la República Argentina, Fundación Síndrome de Down para su Apoyo e Integración, Asociación para el Progreso de la Educación, Federaçao Brasileira das Associaçöes de Síndrome de Down, Fundación Down 21 Chile, Asociación Colombiana Síndrome de Down, Fundación Síndrome de Down del Caribe, Fundación Luisa Fernanda, Corporación Síndrome de Down, Asociación Síndrome de Down de Costa Rica, Fundación Salvadoreña de Síndrome de Down - Paraíso Down, DOWN ESPAÑA, Fundación Integrar Síndrome de Down Honduras, Asociación Síndrome de Down del Paraguay, Sociedad Peruana de Síndrome de Down, Federaçao Nacional de Cooperativas de Solidariedade Social, Federaçao Portuguesa para a Deficiência Mental, Asociación Pais 21, Asociación Down del Uruguay).

FIADOWN considers Art. 19 constitute a huge challenge for people with intellectual disabilities and their families, especially in countries where support and access to services – including education and health – are scarce, inadequate and often of poor quality.

Regarding **paragraph 47**, FIADOWN strongly calls to eliminate it as institutionalization is not acceptable as a choice. Institutionalisation is the opposite of inclusion and contradicts CRPD principle “(c) Full and effective participation and inclusion in society”.

Institutions were originally created to provide care, food and shelter for people with disabilities who were abandoned or regarded as not able to take care of themselves. Research evidence has proven that even if they are successful in providing such care - which is not often the case – they fail to ensure respect for human rights and participation in society. Isolation, solitude, social exclusion and deprivation of meaningful networks are the common characteristics of such institutions.

FIADOWN considers that a General Comment on article 19 should provide a powerful call to states parties to de- institutionalisation and move towards community-based initiatives to promote independent living understood as non-controlled or coerced living conditions were the person with disabilities is in control of their decisions and have freedom of choice to decide how, where and with whom they are willing to live.

This approach to independent living requires to leave behind an overprotective medical approach to disability that impedes the full participation in society of people with disabilities. The need of comprehensive and holistic strategies and policies towards independent living and inclusion in the community must be strongly promoted, ensuring that resources are in place to empower people with disabilities in self-determination and full exercise of their civil, political, economic, social and cultural rights as recognised in CRPD.

Governments services or cash benefits to people with disabilities shouldn’t be conditioned to their living in certain institutions or other congregate living facilities, as it is a way of controlling people with disabilities life’s and limits their right to choose freely.

Support and access to services should be progressively provided as they enhance transitioning from control over the lives of people with intellectual disabilities towards independent living at community level. These support and access to services can include accessible and safe public transportation, personal assistance, respite programs, cash transfers, tax reliefs, and accessible information.

Organisations of people with disabilities – including families organisations’ – should participate in the planning, implementation and evaluation of support services and transitioning strategies and policies.

FIADOWN also calls to take away the phrase “duly justified” from **paragraph 44**, when calling against retrogressive measures on rights already achieved and in place, adducing economic crisis. Gained rights shouldn’t be taken away, especially when much of these measures allows people with disabilities to be included in society and actively participate in their communities.

Finally, we welcome Draft General Comment No. 5 on Article 19: Living independently and being included in the community, as it will surely contribute to a better understanding of a crucial right that intersects with others, mainly with article 12 and its call to equal recognition before the law. The main question for state parties should be how to enhance independent living and full participation in society. To FIADOWN This is one of FIADOWN’s objectives.