CONCEPT NOTE

People with intellectual disabilities and their families during the COVID19 pandemic: Challenges and good practices

1) **Background**

The global crisis of COVID19 created an unprecedented public health, social and economic emergency in almost all countries in the world. From the Global North to South, countries have been more or less affected. The pandemic has revealed weaknesses in existing health systems in many countries in addition to the negative impact it has on education, employment, social protection and economic system, etc.

Although all members of society are affected, people with disabilities are disproportionately impacted. In addition to being more at risk of contracting the virus, of serious illness and poorer outcomes from COVID-19, they face attitudinal, environmental and institutional barriers.

People with intellectual disabilities and their families are particularly impacted. Since the beginning of the pandemic, many people with intellectual disabilities and families have highlighted the challenges they are facing and the solutions they have adopted to cope with the situation.

One key challenge is the lack of access to information and to healthcare services.

In addition, many people with intellectual disabilities and their families are experiencing detrimental impacts from social isolation and loss of support.

The negative financial impact which caused increased stress and mental health issues has also been highlighted by many. They also highlighted the barriers in accessing education, including the lack of support for learners with intellectual disabilities as well as a failure to consider lack of access to internet for many families. People living in institutions are even more affected and some of the stories about what has been happening within the institutions under this lockdown are truly horrific.

Since the beginning of the pandemic, people with intellectual disabilities, their families and their representative organizations are playing an active role in supporting each other’s and supporting the ones who are the most impacted; Peer support virtual groups were created by and for self-advocates, organizations produced regular easy-read information about hygiene measures and important news. People with intellectual disabilities contributed to documenting negative impacts of the pandemic on their quality of life and facilitated actions to mitigate those.

Given the current evolution of the pandemic and its expected long term duration, Governments are continuously reviewing their strategies, programs and budget to face the crisis and reduce its impact on the populations and on the most vulnerable groups. It is essential that all actions by governments in this area be informed by the knowledge,
experience and expertise of people with intellectual disabilities and their families. Therefore, we suggest this platform to hear from people with intellectual disabilities, their families and their representative organizations and to give them space to share their experiences and recommendations.

2) **Objectives**

The objectives of the side event are:

1. To discuss how the pandemic is affecting people with intellectual disabilities and families in different regions/countries.
2. To provide a platform for civil society organizations, organizations of persons with disabilities and other stakeholders to present the solutions and good practices they adopted in order to cope with the COVID19 pandemic.
3. To provide recommendations to Governments and other stakeholders to improve their COVID19 response strategies in order to be inclusive of people with intellectual disabilities and families.

3) **Format**

The event is co-hosted by Inclusion International, Keystone Human Services, YAI Network and Validity Foundation. The World Health Organization and the International Disability Alliance will co-sponsor.

The side-event will be held online on Wednesday 2nd December from 10am to 11.15am (EST).

It will take the form of a panel discussion. The event of a duration of 1.15 hour will include panelist presentations and interactive debate with the audience. The session will be held in English.

To register to the event, please follow this [link](#).

4) **Speakers**

**Opening/Closing Remarks:**

- Ms. Chiara Servili, Medical Officer, Child & Adolescent Mental Health Programme, World Health Organization

**Moderator:**

- Mr. Steven Allen, Co-Executive Director, Validity Foundation

**Panelists:**

- Ms. Fatma Wangare, Coordinator, Inclusion Africa
- Ms. Leela Raj, Project Leader, Keystone Human Services, India
- Mr. Milan Svereapa, Executive Director & Mr. Soufiane El Amrani, Self-advocacy officer, Inclusion Europe
- Ms. Ravi Dahia, Chief Program Officer, YAI Network, USA
- Mr. Luis Gabriel Villareal, AS Down Colombia & Council member, Inclusion International