



Global COVID-19 Childhood Disability Data Coordination: a collaborative initiative of the International Alliance of Academies of Childhood Disability

Verónica Schiariti (lead)¹, Bernadette Gillick¹, Arnab Seal², Cilla Springer⁴, Heather Thomson⁴, Ana Carolina de Campos⁵, Susan Wamithi⁶, Guorong Wei⁷, Alicia Spittle³, on behalf of the IAACD COVID-19 Task Force

IAACD COVID-19 Survey Subgroup Task Force represented Academies:

¹American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)

²European Academy of Childhood Disability (EACD)

³Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM)

⁴South African Academy of Childhood Disability

⁵Latin American Academy of Child Development and Disability (ALDID)

⁶East African Academy of Childhood Disability

⁷Chinese Academy of Childhood Disability

Correspondence to: vshiariti@uvic.ca

The coronavirus disease (COVID-19) pandemic continues to cause major disruptions in service provision, participation, and overall well-being of children and young people with disabilities and their families worldwide.¹⁻⁵ As such, the International Alliance of Academies of Childhood Disability (IAACD) has recently created a COVID-19 Task Force with the main goal of learning and understanding the impact of COVID-19. As part of this effort, the COVID-19 Task Force organized working groups as follows: (1) Surveys Subgroup, (2) Webinar Subgroup, and (3) Resources. All subgroups will unite global information integrating Research and Service Innovations and Optimization.

We, the members of the Survey Task Force working group, are launching the **Global COVID-19 Childhood Disability Data Coordination project** to map out data collection initiatives currently in development or launched worldwide. We are looking for surveys using quantitative and qualitative methods, or a combination of both. Specifically, surveys asking their respondents – individuals with a disability, caregivers, and/or professionals – to report directly on their own thoughts, feelings, and behaviours regarding the impact of COVID-19.

The results of this initiative will be shared publicly with all IAACD member academies, other organizations, and researchers in the spirit of global COVID-19 childhood disability coalition for data coordination and collaboration.



What questions are we seeking to answer?

Based on available survey data,

- what is the short-/medium-/long-term global impact of the COVID-19 crisis on physical health, mental health, participation, education, and financial status of children and young adults with disabilities and their families?
- what are the barriers and facilitators for accessing treatments and services?
- which strategies and innovations are working to reduce the impact of COVID-19 on service provision?

How are we going to achieve our goals?

- We are starting a scoping review of surveys currently in development or launched worldwide related to the impact of COVID-19 on childhood-onset disabilities.
- We are actively engaging the members of all the IAACD academies to share information regarding ongoing or completed initiatives.
- A **surveys data collection form** has been posted on the IAACD COVID-19 Task Force website: <https://iaacd.net/iaacd-covid-19-task-force/surveys-subgroup-2/>. We invite our colleagues to complete the form online. **Please participate!**
- We are going to compare the content of each survey and identify common areas and information gaps – based on questionnaires and final reports. Also, we will identify geographical and cultural needs related to COVID-19.
- We will disseminate the ongoing initiatives to promote participation and facilitate dissemination of completed surveys.

What outcomes do we expect to deliver?

- We will produce a **Global Childhood Disability Data Coordination report** mapping out data collection initiatives describing the impact of COVID-19 worldwide on children and young adults with disabilities and their families.

We acknowledge that there may be methodological challenges when mapping content of surveys that have been created for different purposes, such as different sampling strategies, response bias, timing of data collect – different phases of the pandemic in their contexts, etc. However, we believe there are many benefits of facilitating data coordination and global collaboration, including avoiding duplication of efforts, maximizing resources, rapid dissemination of successful strategies, and planning for future phases of data collection.

On behalf of the COVID-19 IAACD Task Force, we hope you consider participating in this initiative.

For more information about this IAACD COVID-19 Task Force please visit:

<https://iaacd.net/iaacd-covid-19-task-force/>



References

1. WHO (World Health Organization). COVID-19 situation report #77. **2020** Available online: 295 https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200406-sitrep-77-covid-19.pdf?sfvrsn=21d1e632_2 (Accessed on 17 April 2020)
2. Lee J. Mental health effects of school closures during COVID-19. *Lancet Child Adolesc Health* 2020; **4**: 421.
3. Wim Van L, Zachary P. COVID-19, School Closures, and Child Poverty: A Social Crisis in the Making *Lancet Public Health* 2020; **5**: e243–4.
4. Jiao WY, Wang LN, Liu J, Fang SF, Jiao FY, Pettoello-Mantovani M, Somekh E. Behavioral and Emotional Disorders in Children during the COVID-19 Epidemic. *J Pediatr* 2020; **221**: 264–6.
5. Schiariti V. The human rights of children with disabilities during health emergencies: the challenge of COVID-19. *Dev Med Child Neurol* 2020; **62**: 661.