



Global COVID-19 Childhood Disability Survey

Surveys data collection form

Please add information to our growing list of surveys for the **Global COVID-19 Childhood Disability Data Coordination**

What is the name of the survey?

Who is the principal investigator or organization leading the survey?

Which country or region/s of the world are invited to participate in the survey?

Is the survey new (COVID-19-related) or ongoing?

New survey developed in response to COVID—19 (any phase)

Ongoing survey related to disability

Other:

Please provide a description and purpose of the survey in simple language (5 sentences maximum).

Was the survey developed in collaboration with people with disabilities?

Who is the target audience (sample) of the survey? Please mark all that apply

Children with disabilities

Young people with disabilities

People with disabilities

Carer of children and/or adults with disabilities

Professionals

**Supplemental Material – IAACD COVID-19 TASK FORCE Surveys subgroup
Schariti et al 2023**

Other:

What is the date and stage of development (e.g., developing..., launched on DATE..., Completed, START/LAUNCH/COMPLETION DATES...)

Unknown

Completion Dates

Unknown

What is the language/s of the survey?

How will the data be used? Please describe in simple language (5 sentences maximum).

Is there a link to participate in the survey? If so, please include it below

Is there a contact email to participate in the survey and/or for other researchers, community organizations, or potential collaborators to contact for more information?

If the survey was completed, please provide the key findings in simple language (5 sentences maximum).

Thank you for your participation.

The results of this initiative will be shared publicly on the IAACD Knowledge Hub website

Distribution of respondents by world region (Total = 17,230 participants) (Figure S1 below)

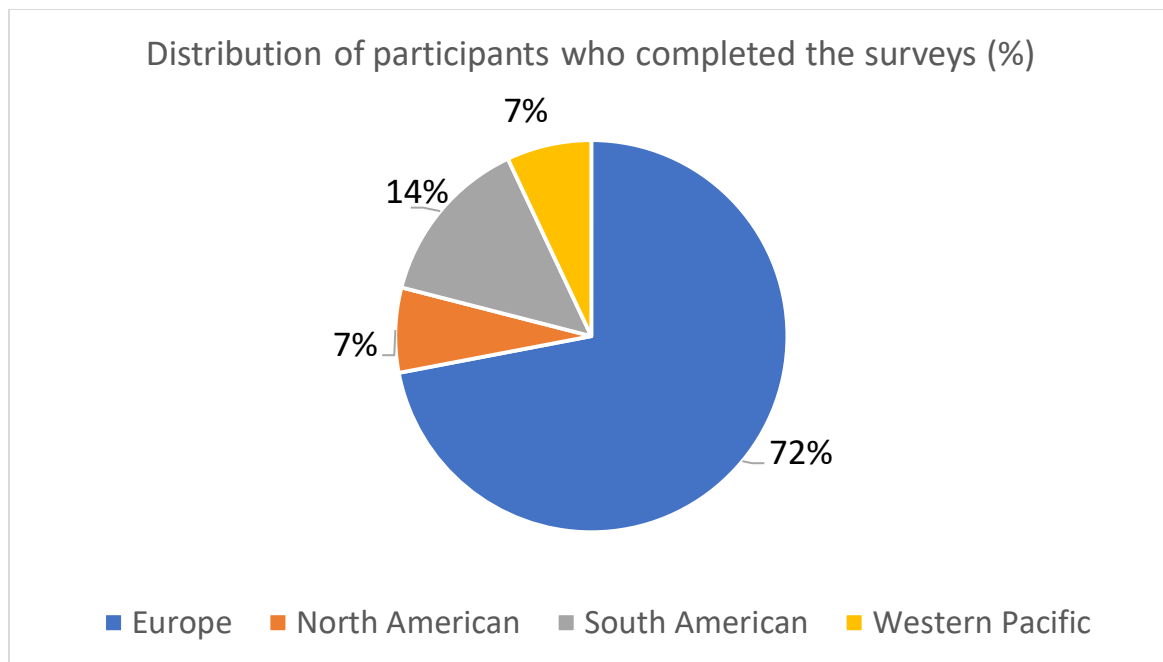


Figure S1. Distribution of respondents by regions of the world

Surveys with highest number of respondents by country/region of the world (10 out of 25 completed COVID-19 related surveys)

Country/region where survey was conducted	Number of participants who responded to the survey
UK	472
China	516
Mexico	556
Australia	700
Canada	1066
Argentina	1296
Spain	1378
France	2000
Europe	3453
UK	4074

Examples of Flash News posted during the project

Global COVID-19 Childhood Disability Data Coordination

FLASH NEWS August 2020



We are seeking to answer:

What is the short-/medium-/long-term global impact of the COVID-19 crisis on physical and mental health, participation, education, service provision, and financial status of children and adults with disabilities and their families?

KEY FINDINGS TODAY

- **32 surveys** identified – more coming!
- **17 surveys** are actively seeking participants – please participate!
- **17 out of 32 surveys** were developed **in collaboration with people with disabilities**
- The most frequently covered **themes** are:
 - Impact of COVID-19 on **mental health** of children and families
 - Satisfaction and experiences with **teleservices** and remote support
 - **Facilitators and barriers** providing tele-consultation and/or tele-intervention.
- Few surveys address a global audience



Created by Dr Schiariti, UVIC, Canada

ADD YOUR SURVEY HERE →



Global COVID-19 Childhood Disability Data Coordination

FLASH NEWS October 2020



We are seeking to answer:

What is the short-/medium-/long-term global impact of the COVID-19 crisis on physical and mental health, participation, education, service provision, and financial status of children and adults with disabilities and their families?

KEY FINDINGS TODAY

- **40 surveys** identified – more coming!
- **20 surveys** are actively seeking participants – please participate!
- Although we identified surveys from all continents, the majority represents: **The Americas (n=16), Western Pacific (n=8) and European (n=8) regions**. Four surveys target a global audience.
- **24 out of 40 collected** information about children with disabilities, the majority by proxy report
- New **themes covered by the surveys are:**
 - Impact of COVID-19 restrictions on employment, housing, and affordability of people with **Cerebral Palsy and Autism Spectrum Disorder**
 - Quality of **remote rehabilitation services** and Continuity of care
 - Impact of COVID-19 on **sleep pattern, mental health and socialization** of people with disabilities



Created by Dr Schiariti, UVic, Canada

ADD YOUR SURVEY HERE →



COVID-19 Links to Ongoing Surveys

Here you can find ongoing surveys that can help understand the impact of the COVID-19 crisis on families and children with disabilities

[Learn more](#)

COVID-19 Links to Completed Surveys

Here you can find completed surveys that can help understand the impact of the COVID-19 crisis on families and children with disabilities

[Learn more](#)

COVID-19 Links to Completed Surveys

EACD COVID-19 Surveys for Families and professionals

The purpose of the survey was to gain more insight into:

- The short-term impact of the COVID-19 crisis on personal and professional practice, ability to provide urgent and non-urgent care, financial status, and the physical health and mental health of professionals and families,
- The current access to treatments and/or services, the availability of certain type of treatments/services, and the effectiveness of the currently provided treatments/services
- Ideas/strategies/innovations aiming to address the experienced problems. How are you adapting to the new situation? What can health care professionals, policy makers, and others do to mitigate the impact?

Status: Completed

Region: Europe

For more information click [here](#).

COVID-19 and Special Educational Needs and Disabilities (CO-SEND)

Children with special educational needs and disabilities (SENDs) are more likely to experience social and emotional difficulties compared to their unaffected peers. The current outbreak of covid-19 presents a particularly challenging situation for some children with SENDs. The primary aims are:

1. Whether and how children's and parent's feelings and behaviours change during the Coronavirus pandemic?
2. Which factors predict these changes in children's and parent's feelings and behaviours?

Status: Completed

Region: UK

Learn more [here](#) or read the [Article](#)

Supplemental Material – IAACD COVID-19 TASK FORCE Surveys subgroup Schariti et al 2023

Stakeholder Perspectives on Re-engaging with Cerebral Palsy Research Studies Following Onset of COVID-19 in the United States

The purpose of this study is to understand motivators and barriers for participating in cerebral palsy related research and considerations influencing potential participants. Participation takes approximately 20 minutes, and questions are focused on participant values as it relates to research, practical challenges they face in participating in DIFFERENT kinds of research studies, and qualitatively what motivates them to be involved.

Status: Completed

Region: United States

[Learn more](#)

2020 COVID-19 (Coronavirus) and children and young people with disability survey

Children and Young People with Disability Australia (CYDA), the national representative organisation for children and young people with disability, identified that Australia lacked a coherent national response for children and young people with disability in the context of the COVID-19 pandemic. They developed a survey to capture the impact of COVID-19 on children and young people and their families and identify unmet needs for resources and information. This process was designed to capture issues relating to COVID-19 specifically, but also to help plan for future emergency scenarios (e.g. pandemics, bushfires, floods).

Status: Completed

Region: Australia

[Learn more](#)

COVID-19 and the reality of people with disabilities in Argentina: possibilities of complying with the considerations of the World Health Organization

The aim of this work was to know if considerations published by WHO can be fulfilled by people with disability in Argentina and if there are differences in their fulfillment between age groups.

Status: Completed

Region: Argentina

[Learn more here.](#)

See attached pdf describing key findings in Spanish, English and Portuguese [here](#).

Your experience with our Teletherapies

Satisfaction survey aimed at families with the purpose of knowing, based on their experience in A.E.D.I.N. – Asociación en Defensa del Infante Neurológico (Association in Defense of the Neurological Infant), how they consider teletherapy as a treatment option in rehabilitation of patients with neuromotor conditions.

Status: Completed

Region: Argentina

For more Information, contact us : cfrangi@aEDIN.ORG or visit <https://es.surveymonkey.com/results/SM-5JCQMw9B7/>

Repercussions of the COVID-19 pandemic in mothers of children with congenital Zika virus syndrome

The aim of this survey was to discuss the repercussions of the COVID-19 pandemic on mothers of children with congenital Zika virus syndrome (SCZ). This study used mixed-methods, carried out with 44 mothers of children with SCZ who answered an online questionnaire between April and May 2020, who underwent thematic content analysis and descriptive statistics, with the application of the paired Student t test.

Status: Completed

Region: Brazil

Supplemental Material – IAACD COVID-19 TASK FORCE Surveys subgroup Schariti et al 2023

Ensuring functionality among PWDs during COVID-19

Impact Assessment of COVID-19 (among aged, people with NCDS and Disabilities):

- Assess the quality, availability and accessibility of health services during COVID 19 outbreak.
- Monitoring the health and functional outcomes of COVID-19 infection among PWDs.
- Study on pattern of responses among vulnerable group.

Status: Completed

Region: New Delhi

For more Information, contact us : bbc4cradle@gmail.com

How children experienced the pandemic

We want to understand how children talk about the quarantine and time spent at home during COVID-19, and to learn the best way to interact with children.

Status: Completed

Region: China

[Learn more](#) or see our findings [here](#).

Parent carers' experiences of lockdown

This survey asks how families in UK had been impacted by the lockdown.

Status: Completed

Region: UK

For more information, click [here](#).

Challenges and alternative options of entry to practice physiotherapy education during the COVID-19 pandemic

This survey is completed to understand the challenges and alternatives of physiotherapy educational programs that students have faced and used during the COVID-19 pandemic at an international level.

Status: Completed

Region: Global (conducted by Taiwan)

For more Information, contact us : jeng@ntu.edu.tw

ECHO (Enfant Confinement handicap besoins / CHILDREN LOCKDOWN DISABILITY NEEDS)

ECHO ("CHILDREN LOCKDOWN DISABILITY NEEDS") aims at drawing a list of experiences, difficulties and needs that emerged during the lockdown for motor disabled children (with or without associated deficiencies), and their families in France.

Status: Completed

Region: France

Pediatric rehabilitation care during the COVID-19 Pandemic in the Netherlands

The Dutch Academy of Childhood Disability performed an inquiry among therapists and pediatric rehabilitation physicians in The Netherlands, to provide insight in the effect of the COVID-19 pandemic on pediatric rehabilitation care in The Netherlands. In an online survey, open questions were asked about the way the governments' lockdown and social distancing measures were interpreted, which therapies and care were considered essential, which care was continued live or using telehealth, and which new forms of care or therapy were implemented.

Status: Completed

Region: The Netherlands

For more Information, contact us : ai.buizer@amsterdamumc.nl

Impact of COVID 19 on neurodevelopment in children with and without disabilities in Argentina

The aim of the survey was to learn about the experience of families with children with and without disabilities under 12 years of age in Argentina during the COVID-19 pandemic. Specifically, the impact on neurodevelopment of their children, describing the areas of development that were most affected and those that *improved*; and situations that have been *facilitators* and *barriers*.

Experiences of students and families receiving long distance services due to COVID-19 (Experiencia de estudiantes y familias recibiendo servicios a distancia debido a la COVID-19)

We designed this survey to receive feedback from parents concerning the new way of long distance services we were now offering due to the COVID-19 pandemic We asked what they thought about the activities we were sending them to do at home, feedback on the quantity of the activities and the information being sent home, usefulness of WhatsApp for communicating, main concerns during the pandemic, how they had been affected in their family dynamics and also economically, what were their main needs.

Status: Completed

Region: Monterrey, Mexico

For more information click [here](#) and [here](#).

Impacto de la emergencia COVID-19 en población con discapacidad intelectual y del desarrollo en España (impact of the COVID-19 emergency on population with intellectual and developmental disabilities in Spain)

Research on the perception of people with intellectual disabilities, their families, professionals and managers of organizations regarding the impact of COVID using four different questionnaires. We have done it in collaboration with Plena Inclusion España. We have a sample of: 1,378 people in total (644 people with ID; 244 family members; 418 professionals and 72 Managers).

Status: Completed

Region: Spain

For more information click [here](#).

The Impact of COVID-19 Restrictions for People With Cerebral Palsy in Scotland

A survey of people in Scotland with Cerebral Palsy undertaken in 2 phases – May and September 2020 to reflect lived experience both during and after lockdown.

Status: Completed

Region: Scotland

Supplemental Material – IAACD COVID-19 TASK FORCE Surveys subgroup Schiariti et al 2023

Impact of disrupted access to rehabilitation and support services on families of children with disabilities during COVID-19

Participants of this survey were caregivers of children with childhood-onset motor disabilities in the United States. The aims of this survey were to: 1) understand the impact of COVID-19 on access to rehabilitation therapies. 2) identify impact of disruptions in access to rehabilitation services on child/caregiver physical and mental health. 3) begin to assess needs and preferences for delivery of alternate/virtual interventions.

Status: Completed

Region: United States of America

For more information click [here](#).

Pandemic Canadian Autism Needs Assessment Survey (PanCANS)

Caregivers of children with ASD and advocates/autistic adults across Canada shared their experiences to help inform on the impacts of the COVID-19 pandemic. The intention was to gather information on the impact of COVID-19 pandemic on autistic Canadians and their families.

Region: Canada

For more information click [here](#).

Association of Paediatric Chartered Physiotherapists COVID-19 Survey

The overarching aim of this project was to capture the PROFESSIONAL AND PERSONAL experiences of paediatric physiotherapists (in particular the members of the Association of Paediatric Chartered Physiotherapists) during the initial period of COVID-19 national lockdown.

Status: Completed

Region: United Kingdom

For more information click [here](#).