CHILDREN WITH DISABILITIES

Ensuring their inclusion in COVID-19 response strategies and evidence generation
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LEAVING NO CHILD BEHIND DURING THE PANDEMIC

Several months into the COVID-19 crisis, the questions above remain largely unanswered. However, evidence is beginning to emerge that points to increased risks for children with disabilities as well as reduced access to services. Understanding such risks and assessing the socioeconomic impact of the pandemic are key to shaping a response that takes into account the needs of all children.

Since the start of the crisis, governments have struggled to meet unprecedented demands. Disruptions to services, ranging from education to child protection, have been documented, with disproportionate effects on the most vulnerable children and families. In many cases, governments have responded creatively and adapted services to address critical needs. Documenting such disruptions along with mitigation measures is central to spotlighting the immediate and long-term interventions that must be put in place to ensure the safety and well-being of all children.

While much has been learned, far more remains unknown. Research and data collection are needed to draw attention to the experiences of children with disabilities during the pandemic, to advocate for a range of services to be available now and in the future, and to inform the design of specific interventions. That said, children and adults with disabilities are likely to remain invisible in data collection efforts, unless dedicated measures are put in place to make such efforts disability-inclusive.

As more data on children with disabilities become available, the insights they offer must be woven into the public discourse surrounding the pandemic so that the needs of these children are considered during the decision-making processes leading to a response.
COVID-19 has disrupted life in every corner of the globe. But while the impacts are far-reaching, the virus and the measures implemented by governments to contain its spread are hitting the most vulnerable children and families the hardest.

Children with disabilities are among the world’s most disadvantaged groups. Stigma and discrimination against them often lead to increased exposure to abuse and neglect, reduced access to services, and general lack of recognition. Moreover, children with disabilities and their families are more likely to live in poverty, and they are overrepresented among the homeless population and those living in residential care and shelters, which further exacerbates their marginalization.

In the context of the COVID-19 pandemic, such children may face heightened risk of exposure, complications and death due to underlying conditions and pre-existing vulnerabilities. They are at higher risk of contracting the virus because they are more likely to live in congregate care and to be unable to practise prevention measures, such as the wearing of masks, handwashing and physical distancing. In general, children with disabilities have greater health-care needs and dependence on community-based services – challenges that generally have not been recognized in pandemic response plans. In situations where services have been disrupted, social inequalities are magnified for persons with disabilities, especially children, since they are often the most reliant on these services for their well-being. In addition, overwhelmed health systems have prompted concern that children and adults with disabilities will be discriminated against in triage and suffer worse health outcomes due to poor medical care.

At the same time, concern is mounting over the inadvertent effects of lockdowns, including increased anxiety and depression, and the exacerbation of pre-existing mental health issues. Such issues can worsen in the absence of community support networks. Changes to and the loss of structure and routines can take a heavy toll on children with disabilities, especially on those with intellectual and/or psychosocial difficulties. Such children may not understand or may not cope well with the sudden and major disruptions taking place or the need for certain preventive measures. Finally, quarantine constraints and the overall burden faced by families may also place children with disabilities at increased risk for violence at home.

For all children, school closures are likely to constitute a major disruption to their daily lives. But for children with disabilities, remote home schooling may be exceptionally difficult. Not only do they require access to the Internet and related technological resources. They may also need assistive devices or special curricula that allow for continued education at home.
What can existing data tell us about the disadvantages that place children with disabilities at higher risk during the pandemic?

Existing data are key in identifying the vulnerabilities that make children with disabilities more likely to experience adverse outcomes during times of crisis. Understanding these pre-existing vulnerabilities can help governments anticipate how the pandemic could exacerbate current inequities. It can also shed light on where targeted efforts may be required.

UNICEF supports governments in monitoring and reporting on child well-being, including the status of nutrition, health, education and parenting practices, through the Multiple Indicator Cluster Survey (MICS) programme.

This section is based on MICS data from surveys conducted between 2015 and 2019 in 24 countries. Results were obtained from an analysis of 24 pooled datasets using adjusted sample weights reflecting both within-country sample design as well as country population size.

Data on children with disabilities were collected using the UNICEF/Washington Group Module on Child Functioning, which measures the proportion of children aged 2 to 17 years with functional difficulties in the domains of communication, hearing, vision, learning, mobility and motor skills, and emotions. By including the module, MICS has become the largest source of internationally comparable data on children with disabilities in low- and middle-income countries.
Safely managed water and sanitation services are fundamental to coping with infectious disease outbreaks such as the COVID-19 pandemic. Children with disabilities are less likely to have access to such services. This disadvantage not only aggravates their risk of being exposed to the virus; it also reinforces their experience of social isolation, loss of dignity, and exclusion from basic human rights.

Existing data show that the prevalence of diarrhoea, acute respiratory infection symptoms and fever is significantly higher among children with disabilities, indicating their increased risk overall for infectious diseases such as COVID-19.

School closures have affected learning opportunities for all children and resulted in increased dependency on home schooling arrangements. The ability of children to continue to learn under these circumstances is compromised for those with reduced access to resources. Available data show that children with disabilities are less likely to have books in their households. They are also less likely than their peers without disabilities to read books and engage in early stimulation activities.

Notes: The analyses above estimated adjusted odds ratios using logistic regressions, with each of the variables as a dependent variable and disability as an independent variable, all of which yielded significant associations at 1 per cent \((p < .01)\). Regressions were adjusted for household wealth. Data on water and sanitation refer to children aged 2 to 17 years. Data on health, children’s books and early stimulation refer to children aged 2 to 4 years. Data on reading or being read to refer to children aged 7 to 14 years.

- 18% less likely to have improved sanitation facilities in their households
- 18% less likely to have improved drinking water sources in their households
- 10% less likely to have water and soap for handwashing in their households
- 1.9 times more likely to have diarrhoea
- 1.7 times more likely to have acute respiratory infection symptoms
- 1.5 times more likely to have a fever
- 57% less likely to have children’s books in their households
- 23% less likely to engage in early stimulation activities
- 32% less likely to read books or be read to at home
DISRUPTIONS TO SERVICES
Notes: Figures have been rounded and may not add up to 100 per cent. The estimate of 36 per cent in the ‘Total’ bar reflects the 56 countries that reported a disruption in access to disability-related health services out of the 157 countries that received the survey. Twenty-nine countries reported no disruption, while for 62, the responses were ‘not applicable’ or ‘don’t know’. Ten countries did not complete the survey; therefore, the number of countries with a disruption could be higher. It is important to note that some countries might have such services, but due to their nascent nature, disruption did not occur. The ‘not applicable’ category is meant to capture situations where a service was not available in a country prior to the pandemic.

**Figure 1.**
Percentage of countries reporting disruptions in access to disability-related health services (such as rehabilitation and assistive technology services)

**OVER 80 PER CENT OF COUNTRIES IN EASTERN EUROPE AND CENTRAL ASIA REPORTED DISRUPTIONS IN ACCESS TO DISABILITY-RELATED HEALTH SERVICES**
AT LEAST ONE QUARTER OF COUNTRIES REPORTED DISRUPTIONS IN SOCIAL PROTECTION SYSTEMS FOR PERSONS WITH DISABILITIES

Figure 2. Percentage of countries reporting disruptions in social protection systems for persons with disabilities

Notes: Figures have been rounded and may not add up to 100 per cent. The estimate of 24 per cent in the ‘Total’ bar reflects the 37 countries that reported a disruption in social protection systems for persons with disabilities out of the 157 countries that received the survey. Thirty-four countries reported no disruption, while for 76, the responses were ‘not applicable’ or ‘don’t know’. Ten countries did not complete the survey; therefore, the number of countries with a disruption could be higher. It is important to note that some countries might have such systems, but due to their nascent nature, disruption did not occur. The ‘not applicable’ category is meant to capture situations where a system was not available in a country prior to the pandemic.
IN AT LEAST HALF OF COUNTRIES SURVEYED, GOVERNMENTS FAILED TO ADOPT MEASURES AIMED AT FACILITATING LEARNING FOR CHILDREN WITH DISABILITIES

Figure 3. Percentage of countries reporting that the government adopted measures around the provision of instruction and devices/materials accessible to children with disabilities (such as sign language for TV/online learning).

Notes: Figures have been rounded and may not add up to 100 per cent. Ten countries did not complete the survey; therefore, the number of countries where governments did not adopt measures could be higher.
IN MOST COUNTRIES, CIVIL SOCIETY ORGANIZATIONS HAVE NOT BEEN ENGAGED IN PLANNING DISABILITY-INCLUSIVE RESPONSE STRATEGIES

**Figure 4.** Percentage of countries reporting engagement of civil society organizations representing persons with disabilities in some level of consultation, collaboration in design, implementation and/or monitoring or assessing of national COVID-19 response plans in key sectors or planning areas.
Methods and data sources

The data presented in this section are derived from UNICEF’s Socioeconomic Impact Survey of COVID-19 Response. The survey collected information from UNICEF’s network of 157 country offices on disruptions in service provision as a result of the coronavirus, at the national level, across different sectors. The 157 programme countries where UNICEF operates include all 138 low- and middle-income countries, plus 19 high-income countries. These 157 countries are home to 90 per cent of the world’s population of children.

UNICEF country offices were asked to provide an assessment of the approximate level of disruption (at the national level) in selected services for persons with disabilities. In addition, country offices were asked about the engagement of civil society organizations representing persons with disabilities in some level of consultation, collaboration in design, implementation, and/or monitoring or assessing of national COVID-19 response plans in key sectors or planning areas.

Data were gathered between 30 August and 22 September 2020 and reflect the situation at the time the country offices submitted the survey. As of 22 September 2020, 147 country offices had provided responses to at least one of the questions pertaining to persons with disabilities in the third quarter round of the survey. Thus, the results reflect the situation in 81 per cent of UNICEF programme countries, which are home to around 1.7 billion children.

Although every effort was made to document and verify the reported level of change, the questions asked were left open to some amount of interpretation. Finally, because the types of services vary by country, respondents used their knowledge of the local context to report on what had occurred and, in some cases, the responses represent best estimates. As a result, figures may not capture the full national response to the COVID-19 pandemic.

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of countries that reported on any of the disability-related questions</th>
<th>Number of countries that received the survey</th>
<th>Response rate (%)</th>
<th>Population coverage (%) out of 157 countries</th>
<th>Population coverage (%) out of 203 countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latin America and the Caribbean</td>
<td>36</td>
<td>36</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Eastern and Southern Africa</td>
<td>23</td>
<td>23</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>East Asia and the Pacific</td>
<td>21</td>
<td>27</td>
<td>78</td>
<td>24</td>
<td>23</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>21</td>
<td>21</td>
<td>100</td>
<td>100</td>
<td>70</td>
</tr>
<tr>
<td>Middle East and North Africa</td>
<td>17</td>
<td>18</td>
<td>95</td>
<td>100</td>
<td>98</td>
</tr>
<tr>
<td>West and Central Africa</td>
<td>21</td>
<td>24</td>
<td>88</td>
<td>94</td>
<td>94</td>
</tr>
<tr>
<td>South Asia</td>
<td>8</td>
<td>8</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>World</td>
<td>147</td>
<td>157</td>
<td>94</td>
<td>81</td>
<td>72</td>
</tr>
</tbody>
</table>
Governments around the world have taken extraordinary steps to slow the spread of COVID-19 and to minimize morbidity and mortality in those who contract the virus. Currently, in the absence of a vaccine, most mitigation efforts are non-pharmacological interventions driven by social and behavioural principles of prevention (such as communication about risk, handwashing, maintaining healthy environments, physical distancing and self-quarantine). And while the intensity and delivery mode of mitigation strategies are defined by governments, uptake and adherence are mostly determined by individual factors. Adoption of mitigation practices may be determined by choice, knowledge and attitudes, as well as by access to specific inputs required to carry out the recommendations. Persons with impairments are likely to face added challenges in adopting such recommendations. For example, those with communication or cognitive impairments may have difficulty understanding the recommendations, those with physical impairments may not be able to independently adopt the required actions, and persons struggling with mental health challenges may actually experience a worsening of their condition as a result of changes introduced by mitigation strategies.

In almost every country, schools have been temporarily closed and remote education programmes initiated. Here, again, children with disabilities face high barriers in accessing adequate learning resources and engaging in learning activities. Obstacles to providing remote education to such children include a lack of personalized education plans, loss of resources provided in schools (such as specialized educators and structured learning environments), and a lack of assistive technologies for learners with disabilities in their homes.

The degree to which children with specific impairments will be able to adopt and benefit from mitigation strategies is thus a crucial consideration during pandemic response planning. Data on which interventions are likely to have differential impacts will help in understanding the modifications required to accommodate the needs of children with disabilities. Using this information can also help in tailoring appropriate new interventions or in adapting existing ones. Front-line personnel, in all involved sectors, need to be trained so that they have the knowledge, attitudes and skills needed to deliver to all children. Specific support should also be provided for caregivers so that they can make any necessary changes to public health recommendations.
The following are selected examples of UNICEF-supported efforts under way to mitigate the effects of COVID-19 on children with disabilities.

**UNICEF Rwanda** helped build the capacity of 45 health providers to ensure inclusive services for persons with disabilities, focusing on public health outbreaks. About 128 persons with disabilities were trained as trainers in COVID-19 and in risk communication and community engagement to support self-help groups and grassroots organizations of persons with disabilities. UNICEF also worked with the Rwanda Biomedical Centre to integrate nutrition messages for parents and caregivers of children with disabilities into existing training platforms and communication materials. These messages aim to improve childcare skills and feeding practices, especially during the pandemic. Ten communication products used during the Ebola crisis were adapted for use by persons with disabilities. And to support online learning, 112 lessons on television were provided with sign language interpretation in August 2020. In collaboration with the Government of Rwanda and Humanity and Inclusion, 7,282 children with disabilities were provided with individual support for learning at home.

In response to the COVID-19 emergency, **UNICEF Georgia** launched a special television broadcast and a Facebook-based platform geared towards helping parents of children with disabilities. The initiative was carried out in partnership with the Government of Georgia, the MAC Foundation and UK aid. Aired by the Georgian Public Broadcasting Company, TV episodes of *The Parents’ Hour* feature experienced professionals providing specific recommendations on challenges that children with disabilities and their families are facing during the pandemic. Topics include how to develop independent living skills, behaviour management techniques, teaching and learning strategies, and parental self-care. Questions from the audience are pre-collected via online platforms to ensure maximum participation from target viewers. A Facebook-based platform was also launched to identify needs, develop content, and provide resources aimed at supporting children with disabilities and their families during quarantine. The platform features Facebook Live segments with the participation of psychologists, experts and parents on a range of topics discussed in the TV programmes.

**UNICEF Lebanon’s** child-friendly messages for COVID-19 safety were shared for the first time in Arabic sign language. The initiative was undertaken in cooperation with local partner Rahma for Special Needs (RSN) and was jointly funded by the Government of Canada and the Bureau of Population, Refugees, and Migration. It is part of RSN’s Specialized Services Programme for Syrian Refugee Children with Disabilities in Lebanon, which receives UNICEF support. Through the programme, a series of videos on COVID-19 have been enhanced and made accessible for children with hearing impairments. Across Lebanon, and through numerous other initiatives, UNICEF is supporting children with disabilities, boosting inclusion and ensuring their access to learning and education.

UNICEF’s humanitarian social protection programme in the **Syrian Arab Republic** aims to enhance the resilience of the most vulnerable families affected by COVID-19, strengthen the continuum of humanitarian and early recovery interventions, and preserve the social protection space around the country. From January through August 2020, UNICEF provided cash assistance and case management services to over 8,100 children with disabilities in rural parts of Damascus, Aleppo, Al-Hassakeh, Homs and Hama.

**UNICEF Nicaragua** provided technical and financial support to strengthen teachers’ capacities to work with families who have children with disabilities aged 3 and younger. Assistance was provided through the Ministry of Education’s Inclusive Special Education Directorate. Separate guides and flip charts on early childhood development and intellectual disabilities were developed for teachers and for parents. Resources were also allocated for the provision of hygiene kits to schools offering special education.

**UNICEF India** continues to provide technical support to state
governments and partners to ensure the continuity of learning at home. In Gujarat, 87,621 children with disabilities (42 per cent of whom are girls) are receiving assistance through the Study at Home initiative. Around 180 educational mini-videos were created to help parents of children with disabilities, and 120 special educators were trained to follow up regularly and support learning.

UNICEF Vanuatu is supporting Wan Smolbag’s Rainbow Disability Theatre to spread messages about COVID-19. The troupe, made up entirely of persons with disabilities, is being welcomed into communities and provides impetus for children with disabilities, along with their parents and caregivers, to participate in COVID-19 information sessions. As of October 2020, the theatre group had reached 2,255 people in Port Vila and Efate with Ministry of Health-approved songs on COVID-19.

Videos produced by UNICEF Mongolia, the World Health Organization and the Ministry of Health are being translated into sign language by the Mongolian Association of Sign Language Interpreters. By end September 2020, 23 videos had been translated and shared through Facebook groups and pages of people with hearing disabilities, generating 22,836 views and 14,989 engagements. The video call interpretation service for COVID-19 hotlines is ongoing and has reached 175 children and adults with hearing disabilities.
Using inclusive approaches in preparing for, mitigating and responding to public health crises such as the COVID-19 pandemic is every government’s duty. Representative data are key to enabling countries to transition through the pandemic’s various stages and to ensure that nobody is left out in present and future interventions.

That said, gathering disability-inclusive data has been a long-standing challenge in many countries. Even in the absence of a global threat, persons with disabilities tend to be underidentified, underrepresented or even excluded altogether from official statistics and monitoring efforts.

During the pandemic, many of the constraints to producing inclusive data have tightened, due to the competing urgency of multiple evidence needs as well as general disruptions to data collection protocols. For example, ongoing monitoring efforts, including surveys and censuses, have been severely affected. National statistical offices in many countries have suspended or are adjusting current operations to protect the health and safety of their staff and the public. Some data collection efforts are being conducted using alternatives to in-person interviews. But while these methods can generate important data, persons with disabilities are still likely to be left out.

To overcome this risk, and turn crisis into opportunity, special consideration should be given to collecting data that reflect the experiences of persons with disabilities and ensure their participation every step of the way. This involves the deliberate adoption of proactive strategies and affects all stages of the data collection process – from study design to the dissemination of results.⁸
START HERE

IDENTIFYING DATA NEEDS DURING THE COVID-19 PANDEMIC

Data are needed for situation analyses, advocacy and data-driven decision-making
What are the pre-existing vulnerabilities that place children with disabilities at higher risk during the pandemic?

Data are required for needs assessments and immediate service response
What services are facing significant disruptions?
How can front-line workers be supported to provide inclusive care?

Data are needed for evaluating the effectiveness of interventions
What accommodations to standard mitigation strategies are effective in addressing the needs of children with disabilities?

Generating new evidence does not necessarily require new data
Can existing data answer your questions?

Data should guide action aimed at addressing the immediate needs of persons with disabilities in the context of COVID-19
Are evidence needs urgent and actionable during the pandemic?

Data collection efforts during crises, such as COVID-19, can excessively burden already stressed statistical systems
Is data collection feasible?

Do not proceed
Reconsider data collection plans

Leverage existing data
• Synthesize existing evidence and showcase lessons from past crises
• Undertake review studies, including mapping of existing services and documented constraints to service delivery
• Analyse administrative data (before, during and after COVID-19)
• Invest in secondary analyses of existing survey data to explore pre-existing vulnerabilities affecting persons with disabilities
• Leverage big data, including from social media

Re-evaluate the immediate usability and actionability of data
Engaging with stakeholders, including organizations of persons with disabilities, to understand their perceived evidence needs can help identify critical data required to inform decision-making and improve the relevance and actionability of the results

Capacities and resources may be insufficient
Statistical offices implementing data collection may have more urgent priorities

NO
YES
YES
NO
NO
YES

18
In the event of a national lockdown and significant movement restrictions, remote data collection can be considered, provided the criteria below can be guaranteed:

Informed consent and assurances of voluntary participation are obtained
A careful evaluation of risks and benefits is conducted, with benefits outweighing risks
Confidentiality and data security are guaranteed

Can you ensure inclusive data collection?
Inclusive methodologies and instruments are used
Inclusive study designs and methods of data collection are in place
Persons with disabilities are engaged at every step of the data cycle

Can you ensure data quality?
Tested methodologies are used
Rigorous data-quality checks (before, during and after fieldwork) are in place
Sources of bias (from the use of the Internet or mobile phones during surveys, for example) are minimized

Plan for longer-term data collection and analyses once the COVID-19 risk is diminished and lockdowns are lifted
Observational data collected once pandemic risks lessen can provide robust insights if adequate statistical modelling takes place. Controlling for confounders, both observed and unobserved, can lead to increased accuracy and actionable predictions that can be used in this or future public health crises

• Consider retrospective data designs, including case-control studies and retrospective cohort studies
• Quasi-experimental studies including instrumental variable modelling and other techniques can help answer questions addressing causality among variables or events
• Multivariate analyses of observational data may not provide answers to questions on causality, but they may yield important evidence on associations between variables of interest and on disparities of specific outcomes across different population subgroups
• Invest in impact studies that can ensure adequate randomized assignment to intervention and control groups. Doing so reduces the need for baseline data that may not be possible to collect now
• Build on existing evaluations (quantitative and qualitative), by formulating additional relevant questions
• Leverage the staggered implementation of interventions and their impacts in various locations (cities, counties, states, countries, for example) for natural experiments controlling for appropriate confounders

If you can ensure these three criteria are met, then you can proceed to carefully plan data collection.

Do not proceed
Biased or low-quality data lead to misleading results
Consider other options to ensure ethical collection of data while guaranteeing data quality
THE OPPORTUNITIES AHEAD

COVID-19 has challenged communities, families and children around the world, raising concerns about health, social and economic prospects. As governments and societies implement strategies to respond to and mitigate the effects of this public health crisis, some long-standing inequities and exclusions have become blatantly visible.

The current pandemic has raised new hurdles for children with disabilities due to their greater health-care needs, higher dependence on community-based and specialized services, and difficulties in adopting general public-health prevention measures. However, these considerations have not been effectively taken into account in many COVID-19 response plans.

As the world navigates the current crisis and its many social, economic and humanitarian angles, the focus on children with disabilities should be sharpened to address inequities. Timely, robust and actionable evidence is needed to guide specific responses aimed at eliminating these inequities and mitigating the negative impacts of the pandemic. Such evidence is crucial to draw policymakers’ attention to the experiences of children with disabilities during lockdown, to advocate for a range of protection services to be available, and to inform the design of inclusive response strategies during the pandemic and beyond.

This unprecedented challenge has also brought a unique opportunity to rethink how data can be generated and used to leverage a strong focus and commitment to the needs of children with disabilities. Concrete steps can be taken immediately, by ensuring that any data collection effort during and after the pandemic incorporates inclusive instruments and methodologies and proactively engages persons with disabilities as valuable stakeholders in all phases of the evidence-generation process. Additionally, monitoring and reporting on programmes and strategies during the crisis need to reflect specific outcomes and impacts for children with disabilities and inform any necessary modifications to accommodate the needs of all children. Finally, the current situation has made clear the need to invest in the validation of remote data collection methodologies and to rebuild data systems to be more inclusive and resilient in the face of unpredictable crises.

Reimagining a better future for children after the COVID-19 pandemic will require commitment and coordinated efforts on the part of all stakeholders to break with past paradigms and reinvent strategies that won’t leave children with disabilities further behind.
ENDNOTES


