



# **Crisis talks**

**Raising the global  
voice of youth  
with disabilities  
on the COVID-19  
pandemic**

**Leonard  
Cheshire**



# Acknowledgements

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# Foreword

We are five youth-led organisations across Africa and Asia with a mission to improve the lives of youth with disabilities in our countries.

It has been more than a year since the World Health Organization (WHO) Director-General officially declared COVID-19 a global pandemic. In the months that followed this announcement countries across the world have faced significant challenges in their response.

We have been driven by a determination to understand how the pandemic has been experienced by the millions of youth with disabilities, like us, in our countries.

Through this research project, we sought to get youth with disabilities talking about the COVID-19 pandemic. The views of youth with disabilities are too often side-lined, and in times of crisis we need to hear from marginalised groups more than ever.

We believe youth with disabilities deserve to be heard. This project provided an opportunity for hundreds of youth with disabilities to tell us their views directly, in their own words, about the situation they faced and recommendations for longer-term recovery.

But this is not just simply about ensuring the protection of all youth with disabilities during times of crisis. It's about seeing the value of youth with disabilities as capable – and more importantly **essential** – actors in finding solutions to the challenges we face.

We have spent our entire lives battling negative perceptions that youth with disabilities have nothing to offer communities. Our organisations were born out of a desire to change the narrative. Through this Leonard Cheshire project we have united to help raise the voice of our peers around the world and show the world what we can achieve.

We hope you find this report insightful, and that it inspires you to join our fight and make sure no one is left behind in the pandemic response. In spite of the pandemic, there is an opportunity to transform the participation of every youth with disability by rebuilding inclusive communities that benefit everyone.

## The Global Research Team

Located in India, Indonesia, Kenya, South Sudan and Zambia





## Introduction

**While pandemics affect everyone, we know from past health emergencies that the poor and most vulnerable are the hardest hit.<sup>1</sup> The findings of this youth-led research have shown that youth with disabilities have faced additional stigma and discrimination during this current time of crisis.**

The research has found that youth with disabilities are often the first to be furloughed or lose their jobs; they have little accessible healthcare information, or confidence in the systems to treat them fairly; and they more often than not feel like second-class citizens when it comes to accessing remote education opportunities alongside their non-disabled peers.

The research has brought glimmers of positivity through the actions of some governments and stakeholders, such as accessible services and favourable cash grant schemes. However, these examples are not nearly as widespread as they should be in order to ensure all youth with disabilities are protected and supported.

The research has also demonstrated that youth with disabilities have not just been recipients of COVID-19 efforts. They have also been part of leading the response in their communities. From distributing personal protective equipment (PPE) or taking to the airwaves to spread health messages, youth with disabilities have stepped up during the most challenging of circumstances. However, stigma still

exists, which prevents every youth with disability from feeling like they can be accepted, let alone play an active role, in their communities.

Response and recovery efforts can only be effective when everyone is equally valued and included, and that includes youth with disabilities.

It is encouraging that some youth with disabilities have been consulted in relation to the pandemic. However, this is not happening routinely. Rarely are youth with disabilities part of government task forces set up to respond to the pandemic.

Urgent action is required to ensure that youth with disabilities are consulted and included in public emergency planning, health response and recovery efforts; that they are seen as actors who can contribute to the rebuilding of societies.

For this to become a reality a multisector approach is needed. The recommendations in this report serve as a reminder, not just to governments but a range of duty bearers, that the strongest progress can only be made when acting together.



## Youth with disability context

**The world today is home to the largest generation of young people in history, 1.8 billion.<sup>2</sup> Around 12% (220 million) are estimated to live with a disability, and they are among the most marginalised and poorest of the world's youth.<sup>3</sup>**

There is no universally agreed definition of a young person and this varies country-to-country. However, for statistical purposes the United Nations (UN) defines youth as persons aged between 15 and 24.

Leonard Cheshire recognises the 'lifecycle approach' to youth, defined as the transition between childhood and adulthood. These are the years when all young people go through physical and psychological maturation, and are expected to complete their education, acquire skills and assume a social identity. All of this will enable them to fully participate in society.

A lifecycle approach allows the factoring in of young people who are likely to be most excluded because they experience multiple discrimination. For example, youth with disabilities can often go through independence processes at a later age compared to their non-disabled peers for many reasons, including community isolation.

This report, therefore, has defined youth according to each country context. For further insight see the **Country context and partner section**.

Little is known about the situation of youth with disabilities globally. The availability of disability and age-disaggregated data is weak. Where disability data is collected it is often of poor quality, meaning that accurate estimates disaggregated by disability and age are hard to come by.<sup>4</sup> Statistical data can also offer little in the way of understanding **what it is like** to be a youth with disability, which is where the importance of capturing lived experience and stories comes into play.

Without data to understand the realities, the situation for youth with disabilities is unlikely to change.

This research project aims to build the evidence base to support youth with disabilities to effectively advocate for their rights. The testimonies and experiences provided in this research constitute impactful qualitative data that helps shed light on the impact of COVID-19 on youth with disabilities.

# Methodology

The aim of this research project was to highlight the realities faced by youth with disabilities during the COVID-19 pandemic. The project was rooted within a community-led approach using action research methodology to raise the voice of youth with disabilities.

This model helped empower youth with disabilities to play a leading role in the project. It was guided by three core principles:

## Capturing lived experience

The research aimed to provide opportunities for youth with disabilities to highlight, in their own words and on their own terms, the impact the COVID-19 pandemic has had on their lives. The project positioned youth with disabilities as 'experts in their own experience', and their stories were treated as qualitative data, which can provide more powerful and persuasive insight than traditional methods.

## Co-creation with young people

All the organisations involved in the project were recruited based on their strong commitment and track record of youth with disability leadership. Youth with disabilities were involved at every stage of the project, from inception to reporting and beyond. This included setting the research questions and how the methodology would be applied in each country context.

## Representation

Youth with disabilities make up a hugely diverse group in society. The research project sought to engage a broad cross-section. The project had a specific focus to include under-represented groups, such as young women and those living in rural areas, whose voices are particularly absent and rarely given attention.



The action research involved:

- Desk-based research – to gain further understanding of national response strategies.
- Peer interviews and focus group discussions (FGDs) – to gain personal insight into the experiences of youth with disabilities.

An open call was made for youth-led organisations to implement the research. This resulted in the selection of partners from India, Indonesia, Kenya, South Sudan and Zambia.

Delivering a research project during a pandemic required careful planning and project management. The project was responsive to changing COVID-19 situations, particularly during the data collection phase, and responded by scheduling online activities.

In-person interviews and FGDs accounted for three-quarters (75%) of activities. The remainder were made up of both online interviews and online FGDs where in-person activities were not possible (e.g. due to the introduction of travel restrictions).

The data collection was carried out between February and March 2021.

The project was guided by two overarching research questions:

1. **How have youth with disabilities experienced the COVID-19 pandemic and how have they contributed to the response?**
2. **What are the experiences of youth with disabilities in being included in COVID-19 national response strategies and what are their ideas for long-term recovery?**

Once the data had been collected, each research team used thematic analysis techniques on the interview and FGD transcripts. This involved the researchers closely examining the data to identify common themes – topics, ideas and patterns of meaning that come up repeatedly.

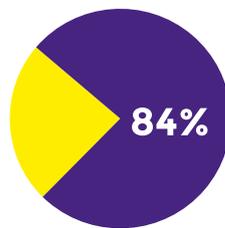
These themes are summarised in the report and illustrated with anonymised first-hand testimonies from participants. The researchers then collated recommendations based on the full analysis for each country, drawing on the ideas put forward by youth with disabilities.



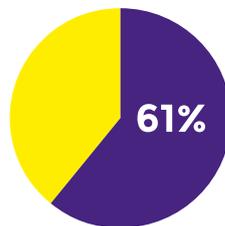
## The researchers

Each partner recruited a research team to carry out activities in the chosen communities which aimed to be as representative as possible of youth with disabilities. The project engaged 31 individuals as part of the research teams across the five countries.<sup>5</sup>

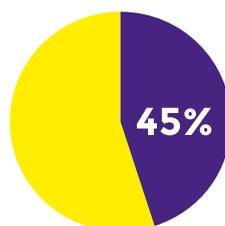
The lead researchers were trained centrally by Leonard Cheshire, on topics such as safeguarding and thematic analysis, and this training was then cascaded to the wider group.



84% of the researchers were young people



61% of the researchers had a disability



45% of the researchers were female

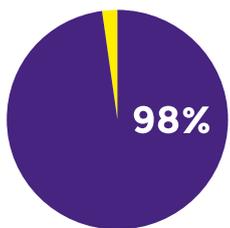




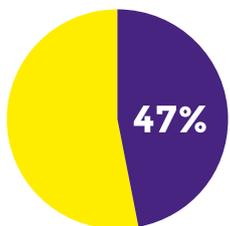
## Who contributed?

The project aimed to reach a diverse range of youth with disabilities and ensure those who are most marginalised, specifically young women with disabilities and those living in rural areas, had an opportunity to participate.

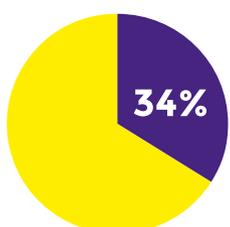
Across the five countries, 545 people participated in the research.



**98% of participants were youth with disabilities**



**47% of participants were female**



**34% of participants lived in rural communities**

This project included the Washington Group Short Set of six questions<sup>6</sup> to capture disability data from respondents. The Washington Group Questions are targeted questions assessing difficulties in six areas of individual functioning. They are intended to provide a quick and low-cost way to collect data which allows disaggregation by disability status. The questions purposely avoid using the word 'disability' within the questions due to stigma and prejudice that can be attached to this label in many societies.

The 545 participants reported experiencing the following functional difficulties:

- Seeing, even wearing glasses: 22%
- Hearing, even if using a hearing aid: 21%
- Walking or climbing steps: 45%
- Remembering or concentrating: 7%
- Self-care, such as washing all over or dressing: 31%
- Communicating (understanding or being understood by others): 8%

# Country context and partners

## India

Young people in India are defined as those aged 15 to 29.<sup>7</sup> They make up nearly one-fifth (19.1%) of its total population. There are estimated to be 8.8 million youth with disabilities in India aged between 10 and 29.<sup>8</sup>

**Ashwini Angadi Trust (AAT)** is a youth-led organisation of persons with disabilities (OPD) based in Bengaluru with the main objective of providing education to differently abled students. The Trust runs on the promise of uplifting the lives of children and youth with disabilities, enabling them to lead independent lives.



## Kenya

Young people in Kenya are defined as those aged 15 to 30.<sup>11</sup> One-quarter (25%) of its total population is aged between 18 and 34. There are estimated to be 1.5 million youth with disabilities in Kenya aged between 15 and 34.<sup>12</sup>

**Gifted Community Centre (GCC)** is a youth-led community-based organisation formed for and led by youth with disabilities in the Kibera informal settlement in Kenya. GCC works for a world where every youth with disability has the opportunity to achieve their full potential and fully participate in all aspects of life.



## Indonesia

Young people in Indonesia are defined as those aged 16 to 30.<sup>9</sup> Over one-quarter (26%) of its total population is aged between 15 and 29. There are estimated to be **over 600,000** youth with disabilities in Indonesia aged between 15 and 29.<sup>10</sup>

**Lembaga Pengkajian & Pemberdayaan Masyarakat (LP2M)** – The Institution of Community Studies and Empowerment – was established to address the subordination of women in cultural values. In its mission to empower young women, it set up the Youths with Disabilities Forum for Leadership and Empowerment of West Sumatra.



## South Sudan

Young people in South Sudan are considered as those aged 15 to 35. Almost three-quarters (74%) of its total population is under the age of 30.<sup>13</sup> There are estimated to be **1.2 million** persons with disabilities<sup>14</sup> in South Sudan, with no clear data for those who are young people.

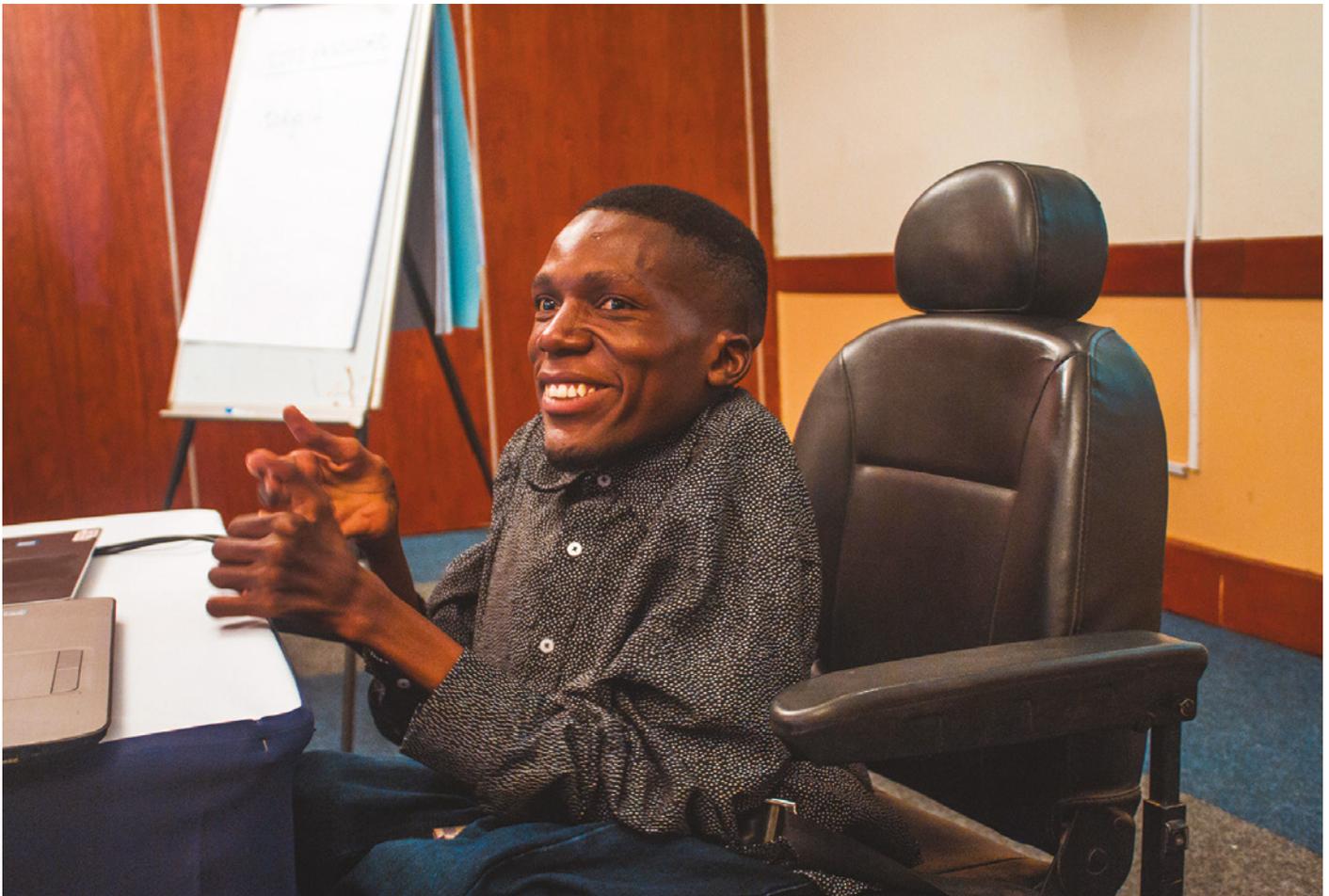
**South Sudan Association of the Visually Impaired (SSAVI)** is a non-governmental, non-profit organisation founded by persons who are blind and partially sighted in 2010. Its mission is to work to combat discrimination and remove barriers faced by persons with disabilities in order to improve their standard of life.



## Zambia

Young people in Zambia are defined as those aged 15 to 35.<sup>15</sup> Over one-third (37%) of its total population is aged between 15 and 35. There are estimated to be over **1 million** persons with disabilities in Zambia, with no clear data for those who are young people.<sup>16</sup>

**Youth in Action for Disability Inclusion of Zambia (YADIZ)** is a youth-led organisation for persons with disabilities formed in 2019 and registered in 2020 with the Zambia Agency for Persons with Disabilities (ZAPD). Its mandate is to advocate for the promotion and protection of the rights of youth with disabilities.



# Findings

## India



**Participants and locations:** 121 respondents from across Karnataka state – including migrated populations from Kerala, Tamil Nadu, Andhra Pradesh, Maharashtra, Madhya Pradesh and Odisha.

**Summary of COVID response:** The Government of India announced a nationwide lockdown to combat COVID-19 under the provisions of the Disaster Management Act (2005). The Disaster Management Act lays down the institutional and coordination mechanism for effective Disaster Management at the national, state, district and local levels. It provides a system that facilitates inclusion at each level.

Activities have been set up by the government to support youth with disabilities. These have included dissemination of information to prevent the spread of COVID-19, distribution of groceries and cooked meals and the distribution of Personal Protective Equipment (PPE). However, these activities have not always reached the most marginal. More needs to be done to involve youth with disabilities in action plan decision-making. Youth with disabilities were not routinely involved in the planning process.

In India, a total of 15,061,919 people had tested COVID-19 positive as of April 19, 2021. However, since the research was conducted, cases in India have risen considerably.

## Key findings:

### The COVID-19 pandemic has affected the wellbeing of youth with disabilities

The pandemic has taken its toll on youth with disabilities, particularly due to money worries. Youth with intellectual disabilities have found it difficult to understand why COVID-19 restrictions have been imposed, causing anxiety for youth with disabilities and their families.

“It was very stressful for me to arrange money to meet travel expenses. I was very scared and nervous as I had very little savings.”

“We are observing severe behavioural change since we are asking him [son with intellectual disabilities] to wear a mask, take bath daily, sanitizing hands, social distancing, and not allowing him to go outside unnecessarily to ensure the safety of my son. He quarrels, shouts, and gets irritated whenever we ask him to follow instructions.”

“

**It was very stressful for me to arrange money to meet travel expenses. I was very scared and nervous as I had very little savings.**

”

## Lack of access to health information and services

The pandemic response has exposed the lack of disability inclusion within planning. The financial strain on families is jeopardising healthcare.

“The information related to COVID-19, like Arogyasetu App, updates on cases, guidelines, protocols, instructions, procedures to be followed for tests and if infected, procedures during medical treatments etc, is not accessible for speech and hearing impaired.”

“Due to financial constraints and unavailability of transport, they [the family of a person with a disability] could not avail their regular medication. As a result, the frequency of seizures increased and she was sacked from her job.”

## Loss of employment for youth with disabilities

Youth with disabilities have found it difficult to retain work during the pandemic, and working from home was not always a viable option.

“Before COVID-19, I was engaged in a group income generation activity promoted by a local NGO. A company outsourced packaging and parcelling work related to garment accessories. I was happy working in a group and with a decent income. During COVID-19, the company stopped outsourcing work due to business loss. As a result there was no income for us.”

“During the lockdown in 2020, I had to work from home. Due to lack of internet facility at home, I was unable to perform well. As a result, I lost employment for three months.”

## Remote learning was not consistently supporting youth with disabilities

While some youth with disabilities were supported to access and benefited from remote learning, this was not the case for everyone. A lack of support to fully engage with online classes left some feeling uncomfortable.

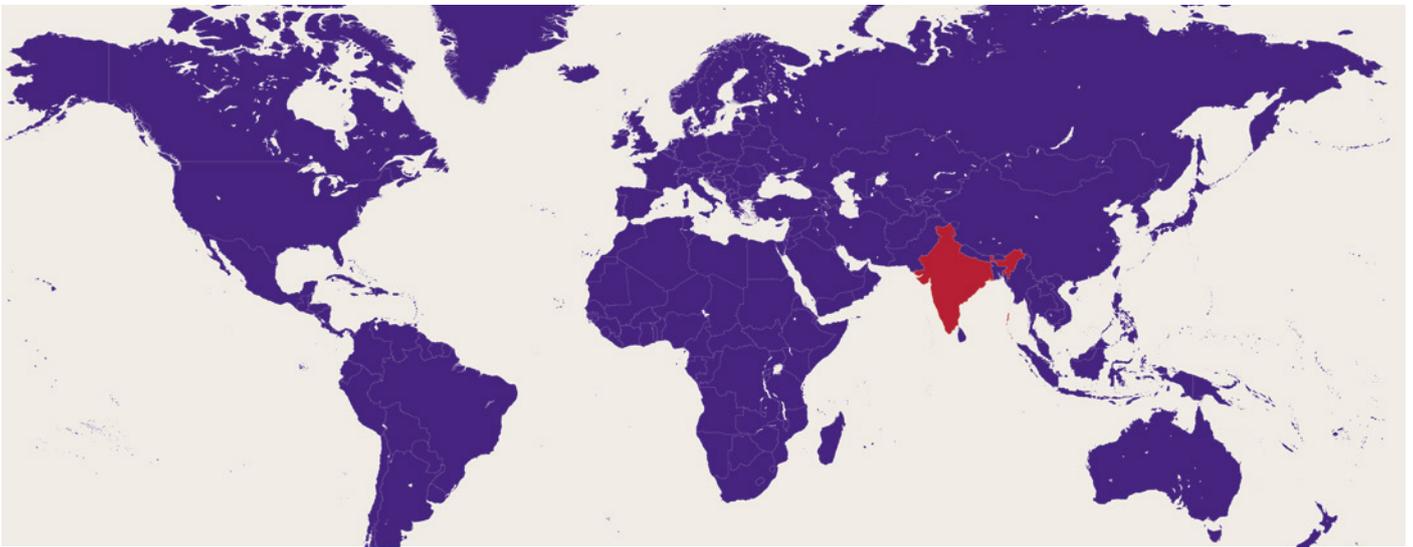
“Due to COVID-19, I have started using a smartphone and a Tab donated by a local NGO to attend online classes. I feel learning through offline classes is more convenient and comfortable for me than online classes.”

“During the lockdown, the lessons taught online were recorded. I had to depend on others to read the PDF attachments. Accessing the textbooks and reference material on different subjects was a challenge as Braille books are available in college only. I faced internet connectivity issues at home regularly. I felt unhappy and isolated without friends and regular studies.”

“

**Due to financial constraints and unavailability of transport, they could not avail their regular medication. As a result, the frequency of seizures increased and she was sacked from her job.**

”



## Recommendations from youth with disabilities in India



- The government should establish COVID-19 task forces for all persons with disabilities, including youth with disabilities and their representative organisations, to monitor the evolving needs during such crises. The task forces can advise on the implementation of inclusive response plans, programmes, and strategies.
- The government should establish inclusive emergency response programmes that address the needs of all persons with disabilities, including youth with disabilities, the specific needs of persons who are blind and partially sighted living in both urban and rural areas, indigenous communities, and those who are homeless.
- Governments, local and national authorities should sensitize the medical teams and other agencies distributing emergency relief supplies and services to persons with disabilities.
- The government should consider increasing disability financial benefits or any other form of disability pension relief during the COVID-19 pandemic.
- Create better awareness of various government schemes and flagship programmes of NGOs for youth with disabilities, and ensure they are accessible.
- Seek training from various rehabilitation institutions to provide services for youth with disabilities during the crisis period, with all necessary precautionary measures.
- Ensure that youth with disabilities have access to employment opportunities in mainstream employment institutions.
- Build awareness and sensitize employers about retaining and creating alternative employment opportunities for persons with disabilities.
- Education ministries should put in a place accessible online schooling systems. They must ensure that parents or guardians of blind or partially sighted and speech and hearing impaired children can fully access education materials so they can provide adequate support to their children.



**Participants and locations:** 100 respondents from four provinces – West Sumatra, East Java, South Sulawesi and East Nusa Tenggara.

**Summary of COVID response:** Various efforts have been made by the government of the Republic of Indonesia to guarantee the rights of persons with disabilities during the COVID-19 pandemic. However, they often do not go far enough and are lacking in implementation.

The first regulation that appeared regarding persons with disabilities in conjunction with the COVID-19 pandemic situation was Government Regulation No. 13 concerning Adequate Accommodation for Students with Disabilities, published on February 20, 2020. Youth with disabilities have been engaged in some task forces.

In addition, the government has also produced several guidelines related to prevention and protection during the COVID-19 pandemic, including one specifically targeted at Deaf students and those with physical disabilities in higher education.

However, more needs to be done to ensure all youth with disabilities engage in the design and implementation of the COVID-19 pandemic action plans.

## Key findings:

### Lack of government assistance for out-of-work youth with disabilities

According to respondents, the government needs to increase the amount of training aimed at increasing the competence of persons with disabilities. They should provide access to employment opportunities and short-term social protection in the meantime.

“What is needed for youth with disabilities, especially those who have graduated from school, is new job opportunities so that young people can be more able to work. Not (seen) as the object of charities and assistance in terms of needs, because working will be much better in the long term.”

“I have not received any social aid from the government. I really hope that the government give more attention to us as persons with disabilities.”



**What is needed for youth with disabilities, especially those who have graduated from school, is new job opportunities so that young people can be more able to work.**



## Online learning solutions are not always disability inclusive or affordable

The research showed that several respondents found the teaching and learning process was ineffective since it moved online. Educators need more support to ensure adaptations to learning environments are fully inclusive.

“Lectures that used to be face-to-face (offline) turned online due to regional and campus policies. When studying, there is access to a Sign Language Interpreter or Typist, but not online because lecturers rarely hold lectures via Zoom, as they only provide learning modules and assignments. The burden with intensive daily assignments increases as the assignments are not accompanied with thorough understanding.”

“It’s difficult for us to study online, especially when we are asked to do more assignments when we don’t have internet data.”

“

**There is a lot of different information, some say that vaccines are good, some are not. So I chose not to be vaccinated.**

”

## Lack of disability-inclusive healthcare services

Respondents were reluctant to go to health facilities for fear of contracting COVID-19, or exposing those who would need to accompany them. Lack of professionalism in the attitudes of healthcare providers towards youth with disabilities was also a factor.

“The inaccessibility of health services to people with disabilities makes me have to be assisted by other people to visit health services. In fact, the person who helps me is also at risk of getting infected.”

“Capacity building aimed at healthcare workers and providers can help with the specific needs of persons with disabilities and their families during this pandemic.”

## Lack of vaccination uptake by youth with disabilities

Less than half of youth with disabilities surveyed were willing to be vaccinated because of a lack of information or existing fears about side effects.

“There is a lot of different information, some say that vaccines are good, some are not. So I chose not to be vaccinated.”

“The government must register the number and the types of disabilities, or at least cooperate with Organisations of Persons with Disabilities to find out whether all disabilities have been registered (for the vaccine programme).”



## Recommendations from youth with disabilities in Indonesia



- Involve youth with disabilities in the process of planning, implementing and monitoring development as well as formulating policies, starting from the sub-district or village level to the national level.
- Collaborate with OPDs to record data on persons with disabilities. Integrate this data into a population database that can be accessed by every department or Regional Apparatus Organisation, private sector and civil society organisation in Indonesia.
- Provide access to employment in accordance with the different disabilities of young people of working age.
- Provide social assistance in the form of business capital. Provide equitable social assistance for youth with disabilities without any discrimination.
- Educate teaching staff to provide a curriculum in accordance with the various disabilities of students.
- Train health workers to be disability-friendly and have a good understanding of youth with disabilities and their concerns. They should use simple language in providing information and ensure the information conveyed does not cause anxiety.



## Participants and locations:

100 respondents from eight regions – Rift Valley, Nyanza, Western, Coast, Central, Eastern, North Eastern, and Nairobi.

**Summary of COVID response:** In June 2020, 6,366 confirmed cases of COVID-19 led to the first government response. This included limiting movement in places with reported cases, closure of public spaces with high human traffic, such as schools and public events, introduction of dusk-to-dawn curfews, and ensuring basic hygiene and social distancing.

Many of the current protection measures, especially around transport and social distancing, make usual means of support and independence risky and challenging to access for youth with disabilities. Some persons with disabilities cannot practice social distancing due to their support needs. Access to information about COVID-19 is often not accessible for persons with disabilities.

Though several reports have been published, little research has primarily focused on the impact of COVID-19 on youth with disabilities in Kenya. The studies instead have focused on persons with disabilities in general.

## Key findings:

### The COVID-19 pandemic has affected the confidence and self-esteem of youth with disabilities

A number of youth with disabilities reported that social isolation, and the consequences of lost education or lost earnings, had affected their mental and physical health.

“I feared to interact freely with people in fear of contracting the dangerous virus. This affected me physiologically since I was stressed for staying long without seeing my close relatives.”

“COVID-19 has lowered my self-esteem. With no mingling, and having to stay long hours alone, the loss of job has really affected me.”

“

**COVID-19 has lowered my self-esteem. With no mingling, and having to stay long hours alone, with the loss of job has really affected me.**

”

## Reduced access to healthcare for youth with disabilities

This included the availability and cost of medication as barriers to healthcare. There was also a lack of information being provided to youth with disabilities.

“When COVID-19 came, my normal medicines were costed highly and this meant I had to stop using them. I also lost my job.”

“When COVID-19 cases were on the rise I went to a certain hospital to seek some services on sexual reproductive health but I did not get the services. When I tried to consult at the reception nobody seemed to notice me.”

## Loss of employment for youth with disabilities

Stigma based on misconceptions about the value and productivity of youth with disabilities as effective employees was heightened during the COVID-19 pandemic. This led to youth with disabilities being among the first to be either furloughed or made redundant in the workforce.

“

**Since I am disabled I was the first employee the company retrenched.**

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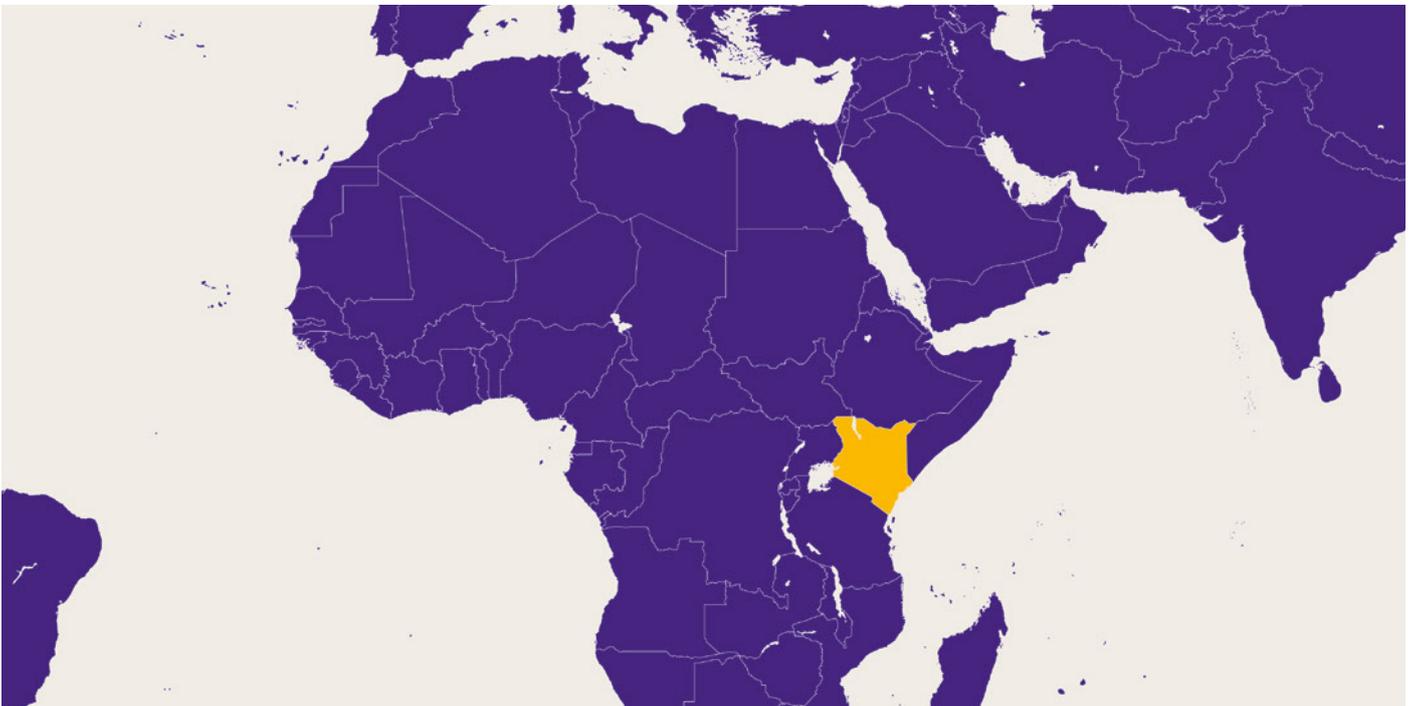
“Due to COVID-19, my employer had to retrench some people and since I am disabled I was the first employee the company retrenched. They thought I was not very productive.”

“I have been affected a lot. I lost my job, then I started my small business, but the city council has been disrupting and pushing me away. I have not even paid my rent as we speak.”

## Lack of youth voice in COVID-19 response planning

The research participants stated that the government had left them out in response planning and were often not effectively included by representative organisations.

“The government only consults the disability representatives at the top level who only air their own interests and then the government concludes those are views for all the youth with disabilities at grassroots level.”



## Recommendations from youth with disabilities in Kenya



- The government should work hand in hand with disability organisations working for youth with disabilities to disseminate information. The government should also make good use of the media that youth receive information from, but invest in sign language interpreters throughout.
- The government should set up inclusive mental health institutions at all levels to ensure youth with disabilities can access mental health services. Support for youth with disabilities should be universal and not only consider those with severe disabilities.
- The government should continually review the policies that advocate for youth empowerment and ensure they are being followed up. For example, the 5% jobs allocations for people living with disability must be fully implemented.
- The government should support youth with disabilities with seed capital/grants to start up small businesses. This should be done through organisations of youth with disabilities or there should be a youth with disability in the offices which are administering the support.
- The government should amend some of the procedures put across in the cash transfer programme to enable youth with disabilities to acquire money without barriers.
- The government should have one central body tasked with airing the views of persons with disabilities. This body should be headed by persons living with disability and include youth with disabilities. The National Council for Persons with Disabilities should work hand in hand to ensure that government support is administered equally.
- Civic education should be administered throughout and not just during pandemic periods.



### Participants and locations:

100 respondents from eight locations: Juba (including Mahad and Mangatain Internally Displaced Persons (IDP) camps), Yei, Yambio, Torit, Bor, Wau, Awil and Bentiu.

### Summary of COVID response:

South Sudan recorded its first COVID-19 patient on 5 April 2020. Up to 28 March 2021 the country had reported over 10,000 cases and over 100 deaths.

In February 2020, South Sudan formed the Revitalized Cabinet of National Unity according to the Revitalized Agreement for the Resolution of the Conflict in South Sudan (RARCSS). However, some parts remain very slow in the pace of implementation.

As the response to tackle COVID-19 progressed, a High-Level Task Force was formed, that was succeeded by a National Task Force. The two bodies undertake the same responsibility. The second differs from its predecessor by the involvement of more technical experts. The task force operates through subcommittees at state and county levels to execute government policy in collaboration with national and international organisations, although the voice of youth with disabilities is often marginalised.

Also of note is that South Sudan has not ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) making the safeguarding of rights of persons and youth with disabilities more difficult.

## Key findings:

### Increased discrimination towards youth with disabilities

Negative perceptions are leading to increased discrimination and are preventing youth with disabilities accessing community services.

“People fear to help us especially when the path is not good, when there is hole, water etc on the way, though they used to do before the pandemic, for fear that we might have COVID-19.”

“I went to the money exchange and was not able to access the building as the entrance was high. No one was willing to assist me fearing that I may be COVID-19 positive.”

### Reduced quality of education for children and youth with disabilities

Not all youth with disabilities were continuing to learn during the pandemic, and those that were did not always find adjustments to classroom learning helpful. Time spent away from school was having a negative effect on whether to return to education.

“The government introduced the distant learning programmes as part of COVID-19 national response strategy which mainly focuses on radio. Youth with hearing impairments are far more excluded. We are not getting it [education] like others although we used to attend the same school.”

“I am now pregnant, and I don't know whether I will go back to school because of family responsibility.”

## Lack of youth with disability engagement in COVID-19 response plans

Many youth with disabilities surveyed felt they had relevant skills and knowledge to play a key role in the pandemic response. However, it was reported there were very few opportunities to get involved.

“Since youth with disabilities have got capacity in handling activities like awareness raising, decision making, counselling and sensitization, we need to be better involved in COVID-19 programmes.”

“When programmes are organised we are often not invited, except in rare occasions in disability-related programmes, despite many issues being related to us.”

## Reduction in income for youth with disabilities

The pandemic has forced many youth with disabilities out of jobs. For example, a small-scale business for therapeutic massage that was run by a group of youth with visual impairments was forced to close.

“We who were engaged in some productive activities such as agriculture and in small-scale businesses, we were capable of sustaining our livelihood before the coronavirus pandemic struck. Unfortunately, majority of us are now in dire need of food and other supplies such as essential items that would sustain us during the lockdown period.”





- The government should implement the existing policies such as the National Disability and Inclusion Policy and Inclusive Education Policy. They should formulate stronger frameworks that ensure the protection of the rights of youth with disabilities. To this end the government should enact disability specific legislation, sign and ratify the CRPD and finalise the long awaited Youth Policy. This will guarantee enforcement of appropriate legal remedies.
- The government should include youth with disabilities in national strategies related to COVID-19 and beyond by effectively involving them and their organisations and considering their views.
- There is great need for more awareness and advocacy on the rights of youth with disabilities during COVID-19. Collective thinking for adaptation of awareness methods is critical to ensure that everyone is equally informed.
- The methods used for education should be diversified to respond to the challenges during and in the post-pandemic phase. This should include provision for learning programmes on TV, production and distribution of radio sets and video recorded materials in sign language and transcription of the curriculum into Braille.
- The government should create more accessible vocational training centres and friendly and accessible work environments. This could include but is not limited to trainings, affirmative action, and provision of subsidies to cover some costs of social and health insurance.
- The capacity of OPDs should be enhanced to reach more persons with disabilities, including youth with disabilities, particularly in areas of advocacy, programming and fundraising to operate more effectively and independently.
- Increased measures are needed to protect youth with disabilities, including training to public service providers such as health workers, and proportionate targeting by the vaccination programme.
- The general and specific needs of young women and girls with disabilities must be addressed, considering the different ways in which the pandemic has impacted this group – in particular by promoting awareness of the rights of women and girls with disabilities and increasing protection measures.
- Universal design and provision of reasonable accommodation should be promoted, including but not limited to public utilities as outlined under the transitional constitution of South Sudan 2011 Article 30.



**Participants and locations:** 124 respondents from three provinces – Lusaka, Copperbelt and Luapula.

**Summary of COVID response:** The first suspected cases of COVID-19 in Zambia were reported on 18 March 2020. Schools were closed, limits were placed on public gatherings, many businesses, including government offices, changed work hours and/or allowed people to work from home to promote social distancing and limit the spread.

In response to the pandemic, the Zambian government developed a national, multi-sectoral COVID-19 response plan and youth with disabilities have been part of the task force. However, there has been little or no research on the impact of COVID-19 on children and youth with disabilities. There is no verifiable data available to demonstrate either the limit or the extent of the COVID-19 impact.

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**E-learning... did not benefit most children with disabilities, especially the blind, because these children’s learning is based on individualised approach.**

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## Key findings:

### Reduced quality of education for children and youth with disabilities

Learners with disabilities reported social distancing, virtual classrooms and reduced incomes were among the issues that had affected learning outcomes and school completion.

“The time schools were closed the government introduced e-learning so that there was continuation of learning, but this did not benefit most children with disabilities, especially the blind, because these children’s learning is based on individualised approach which involves touching learners’ hands.”

“Many parents of children with disabilities have nothing to do. They have no money at all. They can’t send children back to school with this situation they are in. If they fail to get enough to eat how will they afford taking children to school?”

### Reduced access to healthcare

Children and youth with disabilities have been missing medical appointments due to lockdown, increased transport costs or fear of catching COVID-19.

“I used to take drugs for my ears but since the restrictions in movements I am unable to go to Kasanka Rural Health to pick up drugs and this has affected me so much because I am getting completely deaf.”

“The clinic is a bit far from where I stay and I am required to go for regular medical check-ups and collect medication for epilepsy. But from last year I have not been doing so for fear that I might contract COVID-19 at the clinic or maybe on my way to the clinic. I just hope that my health does not deteriorate.”

## Reduced income for youth with disabilities and their families

Most respondents indicated families had been affected economically, since most of them had lost jobs from the time the pandemic started. Both the employed and self-employed were affected financially and this had compromised their quality of standards of living.

“I was fired from work allegedly for low productivity without considering my disability and now I just do small jobs for people.”

“Things are bad, our parents are finding it hard to provide for our needs as well as the needs of other family members, sometimes we fail to have three meals a day. Our parents have no money to take care of us.”

## Social protection schemes are offering some support to youth with disabilities

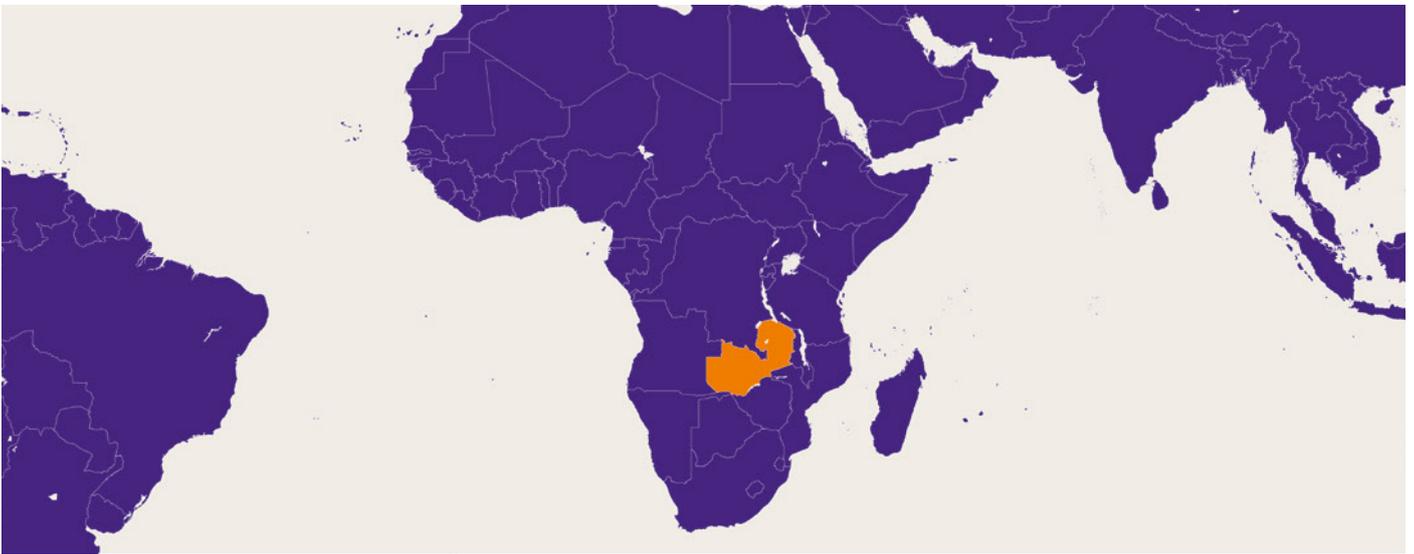
Respondents spoke highly of the Social Cash Transfer (SCT) grant which they said helps meet some basic needs and has made life easier. They indicated that the transfer value has now increased from ZMW 180 to ZMW 600 for households with persons with disabilities affected by COVID-19.

“I am saving some money so that I can do some income generating activities. I used my SCT to acquire a mobile phone, so it is helping. I am now able to buy data which helps me conduct online business and communicate and buy hygiene products like toothbrush, washing powder and the like. I just hope payments are normalized.”

“

**I was fired from work allegedly for low productivity without considering my disability and now I just do small jobs for people.**

”



## Recommendations from youth with disabilities in Zambia



- The government must put in place clear guidelines for disability inclusion in the national COVID-19 response mechanism. It must review the composition and operational guidelines for the COVID-19 response structures at all levels to ensure representation of the voices of youths with disabilities.
- The state must engage more meaningfully with persons with disabilities in all of their diversity, their families and OPDs throughout programme planning, implementation and evaluation. The state should assess the financial and economic impacts and barriers they are experiencing, and identify and implement the most appropriate measures to address them. This should be done as part of all mainstream policy and programme planning, rather than as a segregated response for persons with disabilities.
- The government must invest in accessible and inclusive information communication mechanisms and platforms on COVID-19 to close the information gap between youths with disabilities, other persons with disabilities and the rest of the public.
- Measures need to be put in place to facilitate the timely access to health services for youth with disabilities, such as transportation to healthcare facilities, access to sign language interpretation in hospitals, as well as the procurement of goods, medicines and services.
- Mainstream and disability-targeted social protection measures should be expanded and delivery mechanisms should be adapted to provide adequate relief and support to youth with disabilities and their families.
- Cooperating partners must allocate resources to the development and delivery of youth led interventions to enhance resilience building and promote innovation as we head into the post COVID-19 era.
- Mainstream civil society must develop working collaborations with OPDs to enhance access to advocacy platforms. There must be enhanced collaboration between mainstream youth organisations and organisations of youth with disabilities.

# Youth with disabilities' role in the pandemic response

**Youth with disabilities have the potential to be a part of the solution to the longer-term pandemic recovery in their communities.**

There was evidence from the research that youth with disabilities, and the organisations that represent them, were not content to be passive beneficiaries, but became actors in the pandemic response.

Community contributions from youth with disabilities included everything from reminding friends to abide by health protocols, to disseminating PPE among their community, to making video content and leading radio talk shows to educate and help break the chain of spread of COVID-19.

While circumstances dictated many youth with disabilities interviewed were not in a position to directly support the pandemic response, they nevertheless were motivated to bring change to their communities through raising their voice – and some were doing this for the very first time.

Activities have been carried out individually, with friends, family members, as part of community organisations and in some instances as part of government task forces.

However, barriers still exist. Of those who were not directly involved in the pandemic response, this was for a range of reasons including not knowing how they could contribute or negative community perceptions, and not simply due to the respondent's disability.

Governments and duty bearers must create opportunities for youth with disabilities to be consulted and involved in the pandemic response. Truly resilient communities can only be built back better with the meaningful inclusion of those most marginalised. And that includes youth with disabilities.

**“Because we together must prevent and curb COVID-19.”**

Research participant, Indonesia

## Acronyms

AAT	Ashwini Angadi Trust
CSO	Civil Society Organisation
FGD	Focus Group Discussion
GCC	Gifted Community Centre
IDP	Internally Displaced Persons
LP2M	Lembaga Pengkajian & Pemberdayaan Masyarakat (Institution of Community Study and Empowerment)
OPD	Organisation of Persons with Disabilities
RARCSS	Revitalized Agreement for the Resolution of the Conflict in South Sudan
SCT	Social Cash Transfer
SSAVI	South Sudan Association of the Visually Impaired
WG	Washington Group
WHO	World Health Organization
YADIZ	Youth in Action for Disability Inclusion in Zambia
ZMW	Zambian Kwacha

# Endnotes

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11. National Youth Policy of Kenya, 2006
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