

ARTICLE available at: <https://participationpool.eu/resource/youth-with-disabilities-and-covid-19/>

## Youth with disabilities and COVID-19

*By Karina Chupina*



Photo by [Disabled and Here](#) on [Affect the Verb](#)

**ALT-Text: Photo features a black non-binary person with a disability walking along the street in glasses, mask and with a cane.**

What is it like to be young and disabled during the pandemic? And to continue being active in youth work? What new perspectives can engagement by disabled youth and adults during COVID-19 bring to participation in the post-pandemic world?

In December 2020, „Building back better towards a more inclusive and accessible post-COVID-19 world” was the motto of the [International Day of Persons with Disabilities](#). The struggle for inclusion during the pandemic has presented both critical and encouraging perspectives. While being called the “[world’s largest minority](#)” ([over 1 billion](#)), people with disabilities have historically faced barriers to participation. These barriers were only further exacerbated by the COVID-19 health, social and economic impact that [disproportionately affected disabled people](#). And yet disability still remains an afterthought in crisis responses, despite the evidence that people with it are more at risk of:

- Getting the virus
- Not having full public health and emergency access as well as access to information
- Discrimination and human rights abuse
- Being negatively impacted by the lockdown measures and isolation
- Being denied accessibility as a result of COVID-19 measures ([UN Policy Brief: A Disability-Inclusive Response to COVID-19; Bridging the Gap, 2020](#))

People with disabilities intersect with all representations of identity: racial/ethnic, gender, sexual orientation and gender identity, age, class, religious, and cultural lines. In particular, in COVID-19 pandemic young people and women with disabilities have faced:

- Higher risk of domestic, sexual and gender-based violence (young women with disabilities being unsafe due to breaking the curfew or staying isolated at home)
- Declined access to (accessible) education, employment
- Increased depression and mental health issues on top of pre-existing mental health disabilities or other impairments
- Increased risk of experiencing violence and abuse in residential institutions ([EDF Resolution on COVID-19 and People with Disabilities; UN Policy Brief: A Disability-Inclusive Response to COVID-19](#))

### **Disabled lives matter – yet not consulted in COVID-19 responses**

For this article, I interviewed youth workers with disabilities from different countries about their participation experiences during the pandemic. In line with the [UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#) and “nothing about us without us” principle of disability movements, the [UN Policy Brief: A Disability-Inclusive Response to COVID-19](#) underlines that during COVID-19, disabled people ***“have the right to participate fully... in decisions that affect their lives. They are a diverse, non-homogenous population who possess unique knowledge and lived experience of disability that others do not.”***

However, my respondents or their organisations were not involved in discussions on COVID-19 response measures, which they see as a complete oversight – “the rights of people with disabilities were ignored again”. Naomi Doevendans, [ENIL Youth Board](#) member, trainer, activist (the Netherlands) says,

**“We are fighting for our rights which get violated even more during this pandemic. All that while we remain invisible for non-disabled activists and the governments.”**

Indeed, there has always been a relative insularity of youth with disabilities in the youth sector. Youth with disabilities take it upon themselves to help their peers, fill in gaps in exclusionary systems, run self-advocacy and advocacy initiatives. Organisations of youth with disabilities in Europe emerged, as a rule, as mono- or cross-disability groups who raise awareness about youth and disability rights and mobilise peers. Some networks developed under the aegis of parental (e.g. associations of parents of children with disabilities) or adult organisations. To enter mainstream participation, youth may face obstacles in form of direct or indirect discrimination, lack of enabling environment, community support, accessible education and/or command of a foreign language; low self-confidence, social skills or

competencies needed for youth work ([Chupina, 2014](#)). Youth organisations, on the other hand, can be concerned about difficulties (perceived or real) in including youth with disabilities, which is partially caused by a lack of know-how.

## Visibility of disability, ableism and the pandemic

Both in pre-COVID times and during the pandemic, the needs of people with disabilities have been underrepresented in the media. What makes disability less visible in society is also the fact that [about 70% of disabilities](#) are [hidden](#) (such as mental health issues, chronic pain, intellectual disabilities, autism, hearing and vision loss). Another reason is attitudinal barriers which stem from lack of understanding, misconceptions, prejudices, fears or shame ([NCWD, 2016](#); [Bruijn et al, 2012](#)) and result in stigmatisation, discrimination of disabled people ([UNICEF, 2013](#); [Wapling, Downie, 2012](#)) and ableism. Ableism can be conscious or unconscious, on an individual („I don't want to deal with disabled youth“) or an institutional level, and is deeply ingrained in society because it is not immediately seen or recognised ([Chupina, 2012](#)).

For example, during COVID-19, one could observe an ableist narrative in the media that can be summed up as “only old people with underlying conditions are more likely to die”. The fact that there is a lot of youth who have disabilities or chronic illnesses, seemed to have been dismissed. People with disabilities felt being viewed or treated as second-class citizens. In hospitals, the ableist practices of triage and preferential treatment of more “promising” patients without chronic conditions alarmed disability activists worldwide. Participation by disabled people in decision-making has become the matter of life or death.

## Participation in times of COVID-19 – a right or a privilege?

Participation of youth with disabilities became a daunting test or an unaffordable luxury to enjoy during COVID-19 – but also, at times, a means of valuable self-support. For youth with disabilities, access to participation is very much linked to having their accessibility needs met in daily lives. The main barriers to their participation are attitudinal, environmental (physical, information and communication access) and institutional ([Bruijn et al, 2012](#)). As COVID-19 and response measures disrupted much of this access, the capacity of youth with disabilities to participate declined.

### Physical access:

Movement restrictions have obstructed gathering in conventional participatory spaces. Requirements for social distancing/self-isolation did not allow personal assistants (PAs) or social workers to visit or accompany youth with disabilities in their activities. For example, for a blind person to move from one point to the other, they may need a personal guide who was unavailable.

*“The single disabled parking space I could use was blocked off by tables and chairs [to free space for social distancing inside the venue]”, recalls Marcus Ward, [Spina Bifida Hydrocephalus Ireland](#) - Donegal Branch vice-chairperson, “and hand sanitiser stations were too high for wheelchair users to avail of safely. I contacted the company and these barriers were removed. Many premises have installed one-way systems that help social distancing but are too narrow for a wheelchair to pass through.”* The interviewees stated that putting COVID-

19 safety measures in place shouldn't deny basic access to disabled people – it should be possible to make venues both safe and inclusive.



<https://twitter.com/SongambeleO/status/1246429737943252992?s=20>

The image by [@SongambeleO](#) -

**ALT- Text** The cartoon depicts a dark-skinned man in a wheelchair who lifts up his arms to wash hands in the basin which is still too high for him. The sign on the wall near the basin says “Avoid COVID19. Wash your hands”

Lockdown made some young people feel “*more isolated than their disability or impairments ever had*”, writes [Haben Girma](#), the first deafblind Harvard law graduate. Deafblind people need to touch to communicate, which exposes them to a bigger risk of contracting COVID-19. “*Manual wheelchair users need to touch wheels and floors, blind persons need to touch surfaces, so it is dangerous to go out,*” says Francesca Sbianchi, [European Disability Forum Youth Committee](#) (Italy).

#### **Information and communication access:**

In several countries, people with hearing loss were left in limbo as the televised COVID-19 public health information was not accompanied by captioning or sign language interpretation. They couldn't understand what was happening and what to do. It was often the push from deaf organisations that enabled sign language interpretation in state press-conference broadcasts. Face masks created another huge barrier. To communicate, deaf people need to see facial expressions and many hard of hearing people need to see lips to lip read.



*(Photo: Rafi Nova)*

**ALT- Text: A young man wearing a clear transparent mask is smiling and talking to a young woman in a regular mask who is looking at him.**

To overcome being cut from communication, deaf and hard of hearing youth organisations joined voices together. [IFHOHYP](#) (International Federation of Hard of Hearing Young People) in cooperation with [IFHOH](#), [WFDYS](#) (World Federation of the Deaf Youth Section) and [WFD](#) issued a [joint statement calling for accessible communication during COVID-19](#). IFHOHYP has conducted a Global Survey on the [impact of COVID-19 on hard of hearing people](#). As well, IFHOHYP initiated the first [Global Inventory for Clear face masks](#) so that organisations and individuals could find the masks' providers in their countries. Clear masks that allow seeing a person's mouth, were produced only in the U.S. and a few countries before the pandemic, but COVID-19 has sped up their demand worldwide.

### **The need for self-care, peer support and partnerships:**

The pandemic also made it harder for young people with disabilities to access necessary healthcare, medicines, basic support services (interpreters, repair and maintenance of mobility aids, assistive devices, etc.). Youth with [intellectual disabilities](#) and autism who had their necessary routines and support services disrupted, as well as youth with [psychosocial disabilities](#), developed increased anxiety and depression.

As youth workers with disabilities admit, youth participation has become less of a priority, and understandably so – taking care of one's mental and physical health required more effort than usual. As Naomi Doevendans says,

**“disabled activists need to do their work while dealing not only with inaccessibility and ableism but also their disability. In times of pandemics, this costs us much more energy, time and patience than we have.”**

Women and girls with disabilities are among the most affected groups. Magda Szarota, human rights activist and [Humanity in Action Poland](#) board member, calls for stronger partnerships and says that

**“insufficient solidarity from human rights and feminist movements remains a big problem even during COVID-19. The disproportionate discrimination that women and girls with disabilities face is largely overlooked and the intersectional approach to disability and gender is not widely applied.”**

Some partnerships still attempted addressing gender and disability dimensions, such as [COVID-19 Children and Young People with Disabilities Statement and Recommendations](#) organised by [Include Me TOO](#) and [Commonwealth Children and Youth Disability Network](#) that was supported by several international disability, human rights, women’s, children’s and health organisations. Notable was attention by the [UN Envoy on Youth](#) to the unique perspectives of youth with disabilities in COVID-19 in her thematic [articles](#), [consultations](#) and online events (some of them accessible), including [webinars on young people’s mental health](#) and the [mental health of youth with disabilities](#).

On a different note, in the political participation arena, the [International Foundation for Electoral Systems](#) in partnership with disability networks worldwide has developed [innovative approaches](#) to ensure that people with disabilities continue to have access to participation in public and political life.

The obstacles faced in the pandemic showed that struggles for disability rights need to be fought more than ever. Often, it was this sense of purpose that gave young advocates the strength to continue. One way of doing so has been through online participation. Peer support enabled by online platforms was a mobilizing force for self-determination. When the [European Patients Forum Youth Group](#) realised they needed a morale boost, they decided to introduce an "honesty session" for each online meeting, to speak about how they feel and share their challenges. In a similar vein, [ENIL Youth Network](#) ran a [webinar on Peer support](#) and launched a [Peer Support initiative](#), while [Euro Youth Mental Health](#) shared messages [supporting the mental health of youth](#) in these unprecedented times.

## **Online participation: a universal solution?**

But guess what? Contrary to popular belief, **online activities are not accessible to everyone by default**. There is a lack of (readily available) accessibility tools, services or formats such as live captioning for hard of hearing, sign language interpretation, accessible multimedia, web contents compatible with screen readers for the blind, [alternative texts for images](#), the information in [“easy-to-read”](#) format or pictograms for youth with intellectual disabilities and so on. All these accommodations have to be taken care of in advance, while many youth organisations are not aware of these access needs or do not check with their participants beforehand. Zara Todd, [ENIL](#) senior advisor (Scotland), says, *“Many mainstream providers don't understand what it means to be accessible in an online space... very specifically deaf and hard of hearing youth are being more excluded because organisers are doing things on a short notice and do not think about captioning.”* Marcus Ward shares that *“certain platforms cannot make a person communicating with sign language visible or do not support larger text for partially-sighted people.”*

Social media has become one of the most important communication tools for persons with disabilities in the context of COVID-19 – and they [have been more likely to use social media](#)

[apps for communication than those without a disability](#). It has given an opportunity for disabled youth to express themselves, self-advocate and seek representation platforms. Nevertheless, it is still excluding those with hearing loss, visual and intellectual disabilities due to the lack of accessible formats described above.

Sometimes the youth finds ways to navigate in inaccessible online spaces. For instance, hard of hearing and deaf youth resort to speech recognition apps such as Live Transcribe (Android) to follow online meetings via AI-enabled speech-to-text transcription. Others may need help from non-disabled adults or peers to be able to use technology. As poverty is interconnected with disability ([WHO 2011](#); [Palmer M, 2011](#); [UN DESA, 2018](#)) and COVID-19 has amplified inequality in access to technologies, deepening the digital divide, the lack of internet access or digital competencies became another obstacle for youth with disabilities.

Overall, online participation proved to be both challenging and empowering for youth with disabilities. For those who could not travel or take part in the community, participation suddenly became accessible online. For those who had to rely on a personal assistant's or other support, participation has become easier. In general, youth with physical impairments, blindness and partial sight, [mental health issues and neurodiverse youth have found virtual youth work easier](#). But for many others, being online made everything more difficult or inaccessible.

COVID-19 is an opportunity to improve access to online participation, and this momentum should not be lost – otherwise inclusive participation efforts “for all” fall through the cracks.

## **Lessons learned? Implications of COVID-19 for disability and youth participation**

Dominik Drdul, a young member of the [National Council](#) (Slovakia) claims that „*the pandemic has highlighted how inaccessible our society is*”.

The pandemic has disabled everyone in one way or another as the society was not designed with emergencies in mind. We stayed at home and were isolated, being unable to go out, experiencing the regular lives of many people with disabilities. In this situation, corporations and institutions realised that it is possible to work from home – a prerogative which was denied to numerous people with disabilities before. The work or participation from home can be accessible – and it should not take a pandemic to realise this. COVID-19 pandemic is a tipping point that may lead to disability accommodations becoming more widely available. The society is gradually realising that accessibility (in participation and everyday life) benefits everyone, not just people with disabilities (as an example, [80% of people who use captions on videos in the UK aren't deaf or hard of hearing](#)) and that providing accommodations in education and employment is possible.

**“I feel that many organisations can now better understand the challenges in participation for disabled people,”** says Marcus Ward.



Image courtesy of Marcus Ward (in a blue shirt in the wheelchair in the center) from pre-COVID-19 times: an international youth meeting of the [International Federation for Spina Bifida and Hydrocephalus](#)

**ALT-Text:** A smiling group of young people with and without disabilities is standing in two rows on the background of a large poster that reads “International Youth Conference, 5-6 October 2019”. In the front row, there are two young men in wheelchairs and a girl; in the back row, three standing girls and one young man with a crutch.

One of the positive takeaways from the pandemic is that the role of organisations of people with disabilities has significantly increased. Organisations and networks of youth with disabilities, as well, became sources of information, provided counselling and advice to their peers. All these inclusion and accessibility efforts should be supported to make sure that enabling environment is maintained in the post-pandemic world.

Then young people with disabilities will be able to think „yes, this youth programme is for me, too – I can have access and I am welcome to participate in it“.



## Recommendations

- Deliberate and meaningful engagement of youth with disabilities in the design, implementation and monitoring of all youth programmes from the start, including digital forms of participation
- A strategic approach to an ever-increasing digital online youth activism that takes into account disability inclusion and access needs
- Recognising accessibility as a basis for equitable and inclusive participation for all; acknowledging that accessibility is not only physical and requires a holistic approach to encompass all kinds of disabilities, including in online formats, such as:
  - easy-to-read versions, sign language interpretation upon demand and live captioning services for online meetings and videos; virtual meetings and products adapted to persons with intellectual and psychosocial disabilities and their access requirements (cognitive access)
- Budgeting for inclusion, accessibility and individual accommodations in youth programmes and organisations
- Developing guidance for inclusive participation in youth programmes grounded in real-life practices and proactive measures, and engaging youth with disabilities as facilitators for inclusion
- Building capacity of youth workers, programmes and institutions in inclusive work with young disabled people, also through partnerships with organisations of people with disabilities
- Recognising that participation of youth with disabilities is inextricably linked with social protection, inclusion mechanisms, access to education and training, and healthcare
- In policy formulation and implementation, taking into account acquired mental health issues or psychosocial disabilities such as post-traumatic stress disorder by a larger number of young people (as a result of the protracted trauma of the pandemic)
- Mainstreaming intersectionality in youth participation (without leaving out disability) and recognising multi-dimensional barriers youth with disabilities with intersecting identities face
- Including disaggregated data on youth and disability in policies and programmes in order to improve visibility and participation opportunities for a diverse group of youth with disabilities (young women and girls with disabilities, LGBTQIA with disabilities, refugee and migrant youth with disabilities, asylum seekers, indigenous youth with disabilities, and more) as well as to monitor, capture and evaluate inclusion efforts
- Strengthening narrative on disability and youth – inclusive stories and images at the intersection of disability, mental health, gender identity, ethnicity, race, sexual orientation, origin, location and legal status
- Encouraging and supporting research on disability inclusion in youth work, including youth participatory action research as a tool for empowerment and seeking solutions
- Applying a twin-track approach where relevant: disability-specific programmes for the empowerment of youth with disabilities in safe spaces along with disability mainstreaming programmes
- Making public commitment to disability inclusion on all levels of organisations and developing accountability mechanisms to ensure genuine inclusion of youth with disabilities