

THE IMPACT OF COVID-19 ON YOUTH WITH DISABILITIES IN MONTENEGRO

And disability inclusion in the Montenegro Government COVID-19 response

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Authors:

Milica Marđokić
Goran Macanović
Marina Vujačić
Anđela Radovanović

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ACRONYMS

- Association of Youth with Disabilities in Montenegro (AYDM)
- Centres for social work (CSW)
- Institute of Public Health (IPH)
- Ministry of Labour and Social Welfare (MLSW)
- National Coordination Body (NCB)
- Organisations of Persons with Disabilities (DPOs)
- Organizations for Persons with Disabilities (OPDs)
- Personal protective equipment (PPE)
- UN Convention on the Rights of Persons with Disabilities (UNCRPD)

Introduction

Youth with disabilities in Montenegro face numerous barriers in accessing their rights. Before the pandemic, in everyday life they faced challenges of accessibility in the physical environment and facilities, information, communication and technology, transport and public services. In addition, the lack of developed and diverse community services to support independent living continues to limit youth with disabilities choices and equal opportunities.

As across the world, in Montenegro COVID-19 has impacted significantly on persons with disabilities and their families. The Government of Montenegro is perceived to have responded promptly and efficiently during the first wave of the epidemic that lasted from March to May 2020 to protect public health. The measures to prevent the spread of the virus in the second phase of the epidemic have proven not to be effective in containing the virus and by end of the year, Montenegro had the highest infection rates per capita in the region. The situation has affected all citizens, particularly groups that are inadequately socially included, especially youth with disabilities. Restrictive measures adopted by the public authorities since March 2020 have negatively affected the economy and the standard of living of most people. The Government has adopted several packages to support people and businesses affected by the pandemic. However, no adequate short term (during the crisis for reduction of negative impact) and long term (recovery) measures have been taken that directly target persons with disabilities.

A rapid assessment conducted by the UN system in Montenegro,¹ identified numerous negative socioeconomic impacts of the COVID-19 crisis on persons with disabilities. The report highlighted that the income of families whose members have disabilities had significantly reduced and many persons with disabilities lacked access to regular nutritious food, and hygiene products. Poor Internet access was identified as a barrier that persons with disabilities faced in accessing information. Students with disabilities were identified as being vulnerable to being excluded from education owing to inaccessible remote learning practices. When asked which public services they need most at the moment, people with disabilities and their family members indicated that they needed health services, followed by psychological support, and assistance in finding employment. Some persons with disabilities had additional health problems due to restricted movement, such as rising levels of depression and anxiety.

State authorities in Montenegro do not collect data on citizens with disabilities during census, neither they do other regular data collection processes for the need of adequate implementation of the UNCPRD. Therefore there is no reliable information regarding the number of persons within Montenegro who have disability and no database compiling this information. As a consequence, it is impossible to undertake complete assessments of the barriers for PWDs, their needs, impact, and monitoring of policies and measures. There is limited information on the extent to which young people with disabilities are affected by the pandemic. Hence, this study has sought to gather and analyse data on how the pandemic has impacted the lives of young persons with disabilities. Young persons are defined in this study

¹ United Nations in Montenegro: REPORT on rapid social impact assessment of the COVID-19 outbreak in Montenegro, April-June 2020. The complete report is available [here. Organizations of Persons with Disabilities collaborated with the UN in the collection of data for the assessment, and in the review of the draft findings.](#)

as being between 15 and 35 years of age. In addition, this case study also analyses the level of disability inclusion in the Government's response to the COVID-19 pandemic.

Methodology

For this study, a variety of qualitative and quantitative methods and other tools were used. These consisted of collection of data through questionnaires, 6 interviews, 4 focus group discussions, desk research, seeking information through a request for free access to information², and comparing statistics. Data and other information was collected from 119 persons with disabilities, between the age of 15 and 68 (see table 1), 90 of whom responded through a questionnaire and 29 took part in focus groups, are representatives of organisations of persons with disabilities and employees from various institutions (see table 2). In addition to the questionnaires, personal experiences of persons with disabilities were drawn upon by organizations of persons with disabilities in which the researchers of this case study are engaged. Public information on the impact of COVID-19 and response measures by the Government was also consulted.

The study was carried out from September to December 2020.

Table 1. Characteristics of the respondent (mostly) young persons with disabilities.

Participants	Total	Age	Type of disability and number	Location
Male (M)	60	Under 18: 3	Physical: 56	North: 21 Centre: 82 South: 16
Female (F)	58	Under 26: 30	Sensory: 31	
Other	1	Under 35: 54	Intellectual: /	
		Under 46: 16	Psychosocial: 3	
		Under 57: 12	Multiple: 11	
		Under 68: 3	Rare disease: 11	
		Over 68: 1	Other: 7	
	119	119	119	119

Table 2. Institutions and organisations consulted for the survey

Institutions	Non-government organisations
Ministry of Labour and Social Welfare	Organisations of persons with disabilities (<i>Association of Youth with Disabilities of Montenegro, Union of the Blind of Montenegro, Multiple Sclerosis Association, Association for Support of Persons with Disabilities Bijelo Polje</i>)
Ministry of Education	

² A free access to information is a mechanism defined by the *Law on Free Access to Information* based on the principles of transparency of government, the right of the public to know, equality and is achieved at the level of standards contained in ratified international treaties on human rights and freedoms and generally accepted rules of international law.

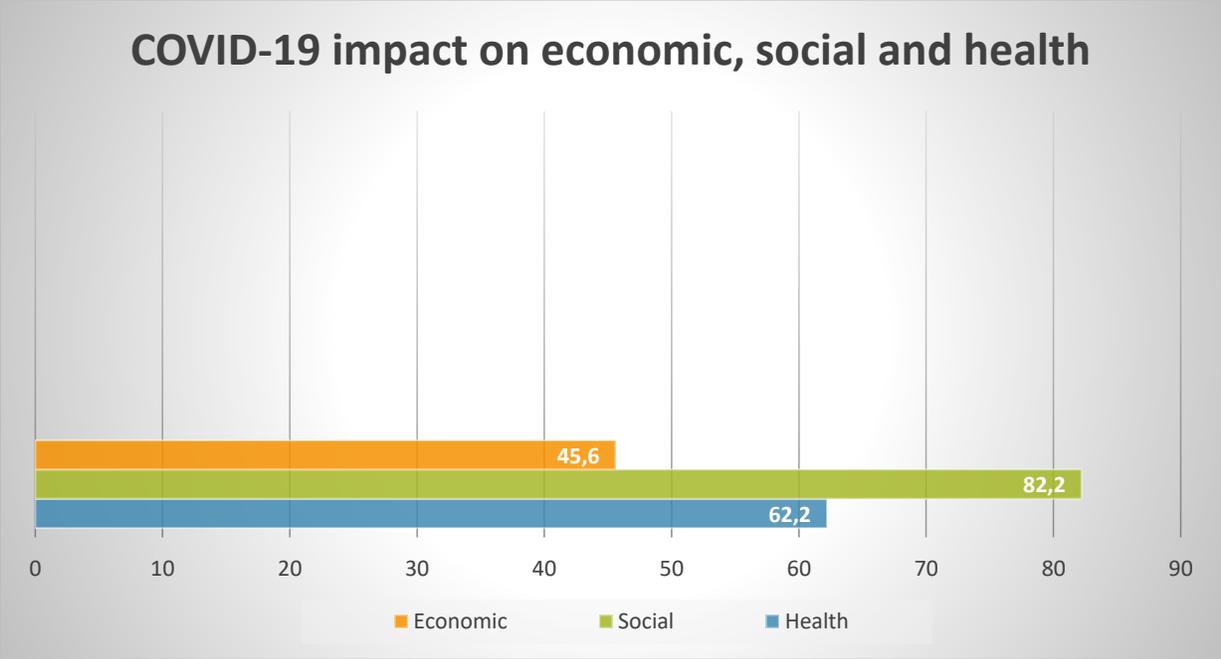
Ministry of Interior	Parents' associations (<i>NGO "Ray of Hope"</i>), <i>Association for Assistance to Persons with Disabilities in Psychophysical Development Nikšić</i>)
Ministry of Foreign Affairs	
National Employment Agency of Montenegro	

Part I. COVID-19 and the impact on youth with disabilities

"We have even lost what we had, let alone got something" – respondent in focus group, F, multiple disabilities, North

Youth with disabilities consulted for this study reported the negative impact of COVID on their enjoyment of a range of rights. Almost half (43.3%) of respondents (a total of 90 persons – 67 youth with disability) reported being deprived of their rights during the outbreak. Besides the restriction of movement, social, sports and cultural life, youth with disabilities lacked access to regular health protection, assistive devices, rehabilitation services, education, employment and the right to information (due to lack of accessible formats of communication including sign language). The barriers that youth with disabilities faced in accessing these rights are explored in this study (see the corresponding sections below).

Chart 1 (Participants were able to choose multiple answers to the question "How COVID-19 particularly affected you?")



Respondents to the survey reported that those most severely affected by the pandemic were persons with hearing and/or speech impairments, persons with intellectual, psychosocial and multiple impairments, and persons with chronic diseases. The last two categories were considered as most severely affected in case of contracting the disease, while

the first three were seen as being unable to protect themselves due to inaccessible health and prevention information and structures for protection and denial of social protections.

When asked what was particularly negative during the epidemic, respondents' replies included the following:

"Way of life and daily routines, a lot of restrictions without systemic support", F, under 35, Rare disease, Centre

"Life moved to the internet, and internet platforms are not that accessible", F, under 18, Multiple Disabilities, Centre

"Cutting down on all possible expenses, except for food", F, under 46, Sensory disability, South

"During the restrictions, only one passenger was allowed in a taxi, so I went nowhere lest my mother is on her own", F, under 57, Physical disability, North

"It happens that I cannot get up, and during the COVID-19 pandemic I had no one to call. Before, I had nurses coming for home visits", F, under 68, Physical disability, Center

a) Health and Rehabilitation and personal protective equipment (PPE)

62.2% of persons with disabilities (of the total of 90 covered by the questionnaire, of which 56 were young people with disabilities) surveyed experienced negative health impacts during the pandemic. Reasons included: contracting the infection, deterioration in existing conditions owing to reduction in access to regular health care and medication, reduced access to medical equipment and assistive devices and deterioration in mental health owing to anxiety and fear of catching COVID-19. Persons with respiratory system limitations reported additional health problems when wearing a mask, which were prescribed in Montenegro as mandatory in public spaces, without any exceptions, otherwise, they were in risk to pay a fine.

"The medication approved by the Ministry of Health was either supplied late or was not supplied at all in Montenegro, which meant the therapy I needed was also administered with delays." – (M, 32, Rare disease, Centre)

Disruptions in access to regular healthcare identified by the sample group as having a greater negative impact to their health than contracting COVID-19. Some healthcare and rehabilitation services were completely suspended. Access to these services was also disrupted as those surveyed were reluctant to use services through fear of becoming infected with COVID-19. Disruptions in medical supply chains also had a negative impact on health. One respondent commented, *"Because of disruptions in the medical supply chain, I had to halve the tablets or had my dosage reduced by my doctor for the medication to last until it came from suppliers abroad"*. (F, 25, Rare disease, Centre)

Access to medical equipment and assistive devices, was also negatively impacted. For persons who use medical equipment and assistive devices made abroad, access to these devices was interrupted as the import of medical equipment was suspended. Some services were suspended directly denying respondents' access. Moreover, respondents were reluctant to attempt to access these services owing to the increased risk of infection posed by the multiple face-to-face appointments required to access assistive devices (including an appointment with a general practitioner, then a specialist, sometimes to a consultant at the Clinical Hospital Center or other institutions such as to the Health Insurance Fund and the supplier of aids). When asked what was the most negative impact of the pandemic one

respondent stated: *“Having no access to the right to assistive devices - because it was impossible to collect the (necessary) medical documents”, F, under 46, Physical disability, Center.*

Youth with disabilities surveyed reported having to carry the burden of increased health costs and this having a negative impact on their overall economic stability. Health costs increased owing to having to source alternative, often more expensive, medical supplies because regular sources of these supplies were interrupted by the movement restrictions, as well as closed borders and restrictions on the import of medical devices and equipment. Youth with disabilities also incurred expenses for vitamins and other medication to increase their immunity. Furthermore, respondents had to cover the costs of personal protective equipment (PPE), as they were not directly covered by virus containment measures that included donations in PPE. Only beneficiaries of care and disability assistance allowance were given some PPE but even this was limited to just two, one-time-use masks. One interviewee testified that, *“First, my expenses increased, due to the current situation, I bought various vitamins and pills to strengthen my immunity. Second, it slowed my recovery because it prevented me from going to rehabilitation in other countries.”* (M, under 35, Physical disability, South)

b) Impact of movement restrictions and social distancing:

Movement restrictions and social distancing reduced respondents’ ability to undertake physical activity and to see family and friends with many reporting a negative impact on their physical and mental health and a feeling of isolation. Overall, 82.2% of respondents reported that they were severely affected by the epidemic’s negative social impact (of the total of 90 covered by the questionnaire, of which 65 were young people with disabilities). Persons who have hearing impairments pointed in particular to problems relating to face masks as these have significantly exacerbated communication issues, leading to additional self-isolation of these persons. Persons with visual impairments reported the negative impact of movement restrictions as it limited their use of accompanying persons.

The “one person rule (unless family)” meant that youth with disabilities who relied on the assistance of another person were left without any support to carry out day-to-day necessities. In the later phase of the pandemic, the one-person-restriction was amended to allow for assistants who were not family members to accompany persons with disabilities. In the later phase of the epidemic, these measures were changed to a certain extent, taxi service was enabled, while only wheelchair users and people with autism have been allowed with an accompanying person, during a stay in a public place and during a restriction of movement for a maximum of 60 minutes.

Youth with disabilities who do not have a driving licence were particularly impacted by the reduction in public transport and the suspension of taxi services as although travel permits from an employer or doctor did override movement restrictions, these permits did not extend to drivers.

Thanks to advocacy efforts by DPOs/OPDs, movement restrictions were eased at certain times for two categories of persons with disabilities, wheelchair users and those with autism. This easing of the restrictions to limit the negative impact on those who would be disproportionately affected demonstrates the positive measures states can take to reasonably accommodate the needs of persons with disabilities. Nevertheless, the

restrictions remained in place for all other categories. DPOs/OPDs interviewed in this study reported being contacted by many concerned parents of young persons with intellectual and psychosocial disabilities, who were finding the restriction impossible to observe without having a severely negative impact on their child's wellbeing.

In addition, in some time intervals, according to the measures put in place by the Ministry of Health, movement restrictions did not apply to those "taking care of persons who for reasons of illness, condition or consequences of an injury are unable to live independent daily lives, which is proved by a letter of their selected doctor. Another required proof is an extract from the civil register showing the two persons are related by blood, or a contract of care or maintenance showing the legal relationship between those persons". It is not only that the exception to the measure is defined in a way which takes into account the health aspect only and therefore ignores the right to personal assistance or assistance in home, but also the measure, defined in this way, poses a challenge for all persons with disabilities who do not have contract-based assistance but are instead paying for an assistant themselves, by the hour of the assistance provided (Article 19 of the CRPD).

In response to movement restrictions, online services were introduced by both public authorities as well as private service providers. Respondents reported that online services and online content were not all accessible. Indeed, even the Guide through electronic services, developed by the Ministry of Public Administration and published by a print media, was not compatible with screen readers and accessible for people with visual impairments. Respondents reported that the lack of accessible online services and information left them behind in accessing information about the pandemic and forced them to be dependent on other people for access to services and information.

Youth with disabilities living in social and childcare residential facilities were left particularly vulnerable and isolated as a result of the movement restrictions. All visitations to residential facilities were suspended, including visits by family members. Authorities argue that these measures were positive and helped contain the virus, but families argue that visits should have been allowed to continue upon a negative COVID-19 screening test because the prohibition on visitors has had an extremely negative impact on the mental health of these living in residential facilities. There is no transparency regarding the situation within institutionalised setting in Montenegro, no official data is gathered, therefore no assessment can be made as to the true scale and impact of COVID-19 on those living within these settings.

c) Economic impact

Almost half (45.6%) of persons with disabilities (of the total of 90 covered by the questionnaire, of which 38 were young people with disabilities) who took part in the survey experienced a negative economic impact from the pandemic, meaning a decrease in income or an increase in the cost of living, or both. 51.1% of respondents (46 of which 33 are youth with disabilities) reported their expenses during COVID-19 remained the same as before the pandemic, 36.7% (32 of which 24 are youth with disabilities) said they increased after the outbreak, while 12.2% (11 of which six are youth with disabilities) said they decreased on account of those activities that they were no longer participating in (such as sport, socialising and other hobbies).

The majority of respondents reported that their general expenses were greater than their income. Increased costs include health care and medical supplies, assistive devices to allow for remote working and online education, accommodation, PPE and higher transport costs. Respondents also reported increase in expenses due to their disability, as they for example, chose to shop in small markets in their neighbourhood as they could more easily communicate with shop assistants who they knew in person. The price of goods in these small markets are higher than in supermarkets where information and communication was not as easily accessible.

Some respondents reported they had lost jobs and employment opportunities or had reduced income. 8.3% of young persons with disabilities surveyed did not receive regular income during the epidemic, as they work in the private sector and their business operations slowed down, or because their activities have been closed due to measures taken by the Ministry of Health to prevent the spread of the virus, or because they were paid their wages with a three-month delay. Government subsidies for employers³ who employed persons with disabilities were also three months late (August, September, October), which negatively affect regular payment of wages to persons with disabilities.

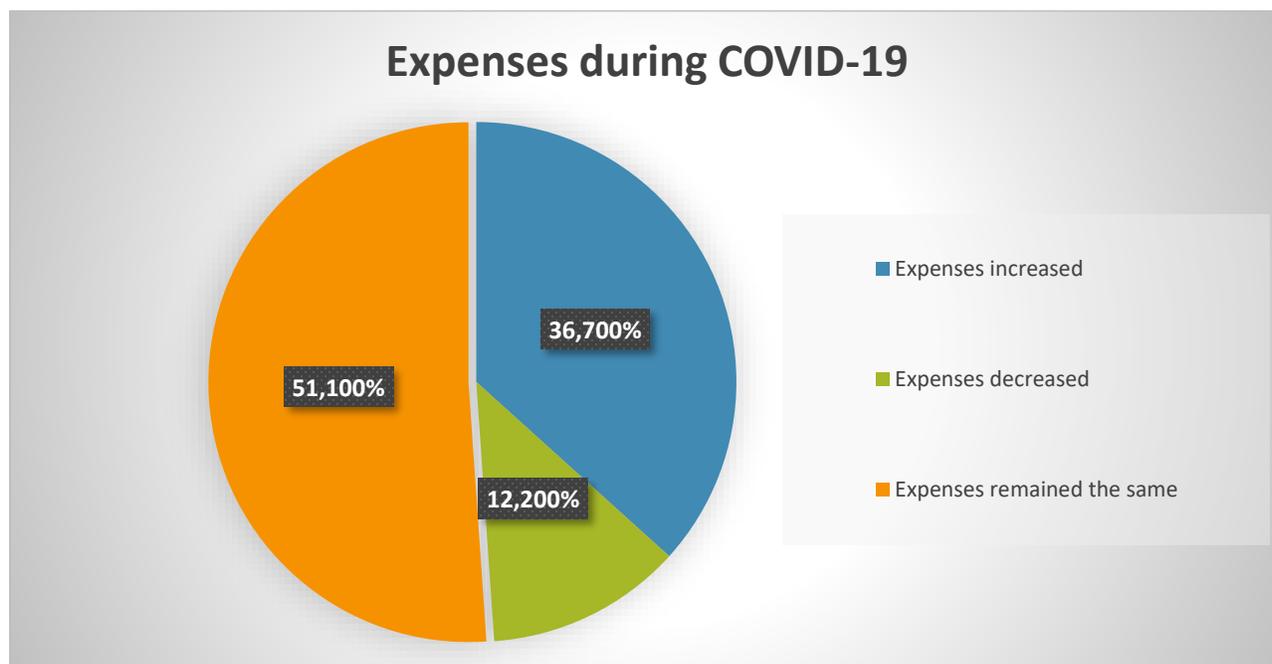
“Considering that I am a freelancer (language teacher), I had significantly less engagement, and in one period I had no job at all. Now, I am having one more job, but without contract and insurance, and I am paid for it depending on the outcomes, with regular payments.” - F, under 35, multiple disabilities, Centre.

Respondents found it was positive that their employers allowed them to work from home, following the recommendation of the National Employment Agency of Montenegro. However, the Agency does not hold, nor can it hold, data on employer compliance with this recommendation given that the measure was not mandatory, and that the competence for monitoring the observance of labour rights rests with the Labour Inspection. In addition, some respondents reported that during the epidemic they could not enjoy their right to reasonable accommodation at work, specifically assistance at work and assistive devices in the workplace, even though they had requested such support over half a year before.

Students with disabilities reported the particularly negative impact of the closure of dormitories which provide both accommodation and meals free of charge under a memorandum of cooperation between AYDM and the administration of the dormitories. Students with disabilities who were residing in a dormitory were forced to find private accessible (which is more expensive) accommodation and cover expenses for food, when the dormitories were closed.

³ The state guarantees employers who employ PWDs the right to a subsidy for part of the wage.

Chart 2. Answers to the question: Did your expenses reduce, increase or remain the same during COVID-19?



DPOs/OPDs have also been negatively impacted by the crisis. There has been little to no financial or resource support provided to DPOs/OPDs by the state, meaning some have had to suspend their activities. Representatives of DPOs/OPDs reported that the pressure from the beneficiaries and expectations for assistance to be provided by DPOs/OPDs were high owing to the suspension of public services, right at a time when DPOs/OPDs own resources were at them most stretched.

OPDs and DPOs were not covered by financial support measures as they were not categorised as 'entities affected by the outbreak'. Therefore, their employees were not entitled to subsidised income as were employees from other sectors (private sector and entrepreneurs). In addition, although medical supplies and equipment was distributed to some businesses and other enterprises, DPOs/OPDs did not receive such support. Instead OPDs and DPOs that continued to operate throughout the crisis had to cover the additional expense of PPE for either their own employees, or their beneficiaries (including beneficiaries working in businesses who did not provide PPE despite this being the responsibility of the employer).

d) Education

To decrease the spread of COVID-19 schools and other educational establishments were closed and education was moved to remote, online learning. However, no prior assessment was undertaken as to the impact that this would have on children and youth with disabilities and the barriers that they may experience in accessing online education. Those surveyed reported children with disabilities were largely excluded from online education as

they were not provided with assistive devices, Internet connection and adequate assistance in the teaching process. Parents reported having to buy internet packages and additional equipment including assistive devices. Students with disabilities reported online learning was difficult at times because of problems with their Internet connection, but also because it negatively affected their concentration. Furthermore, children in rural areas received print materials, as Internet connection was not available to them, however these materials were not developed in accessible formats. The longer-term negative impact of this break in education for children with disabilities will be reflected during the continuation of further education, but also competitiveness on the labour market.

The Ministry of Education did not accept UNICEF recommendations that every school should organise teaching and decide on teaching methodologies on its own, but switched exclusively to online learning.

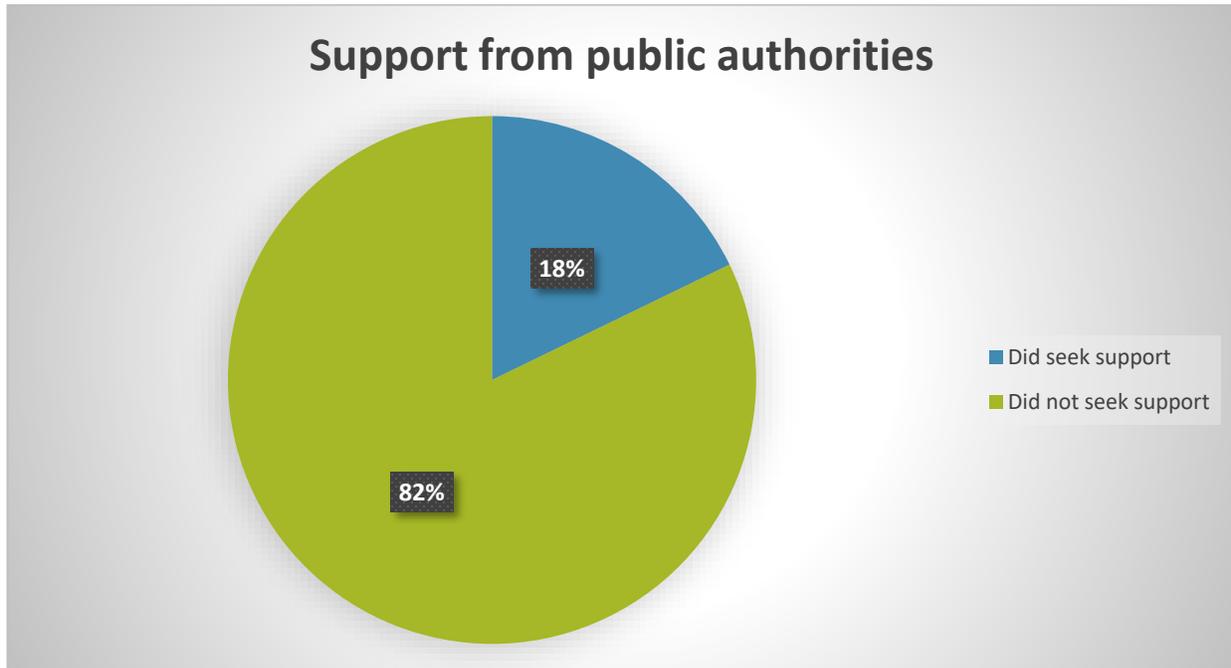
Organisations of parents of children with disabilities complained about the effects of online learning. The Ministry of Education reported it has developed diverse teaching materials to support education during COVID-19 (published on skolskiportal.edu.me), and that teaching assistants have offered support both online and during consultations at school, while the Ministry was against teaching assistants making home visits.

e) Social protection and reduction of negative impact measures

Respondents to the survey detailed the administrative and procedural barriers that prevented many persons with disabilities, including youth, from accessing the social protections that they are entitled to. Out of the 90 respondents to the survey only 16 (nine youth with disabilities) had approached the competent authorities for some kind of assistance. Of the 16 that had sought assistance, four received financial support while 12 (seven youth with disabilities) did not receive a reply from the authorities. Both youth with disabilities surveyed and DPOs/OPDs report that authorities are often slow in responding to assistance requests (some reported waiting nearly six months for responses) and often do not reply at all. Some suggested this was the result of discriminatory attitudes towards persons with disabilities by state officials.

Disability allowance was accessed only by 23.33% of respondents covered by the survey, 56.7% of them are user of the right to care and assistance of another person (material benefit), while 35.6% of respondents accessed the utilities allowance that beneficiaries of the right to care and assistance allowance and disability allowance were entitled to. Complex administration, costly burdensome mandatory procedures and the associated risk of infection while going through the administrative and procedural requirements which involved multiple face-to-face appointments, were stated as reasons those surveyed did not try to access this support. For some, the cost of these mandatory procedures (including travel costs to appoints) prevented them from applying for support. Where support could be applied for electronically, computer illiteracy and lack of IT equipment was a barrier faced by some persons with disabilities, particularly from low economic backgrounds. This pushed them further into poverty. The same barriers were encountered to avail of the utilities allowance (accessed by 35.6% of respondents) and travel subsidies. One-off financial support payments were made on an ad hoc basis by authorities, while food and grocery parcels were distributed by the humanitarian organisations to persons with disabilities struggling to access basic provisions.

Chart 3. Answers to the question “Have you addressed someone for support?”



State institutions, like social welfare centres reorganised the work of day care centres for children and adult persons with disabilities and older persons and tried to meet some basic needs of persons with disabilities living in their community. Persons with disabilities with poor financial status or no family support were given one free hot meal a day, delivered to their homes by the staff of the day care canthers.

In many instances it was OPDs and DPOs that stepped in to fill the gaps left by inadequate and inaccessible social protection. Many respondents reported seeking support from OPDs and DPOs for the first time. Besides legal and psychological support, support in food and services, some organisations reported they were also able to provide medical supplies, as well as internet packages and IT equipment for their beneficiaries. However, all DPOs and OPDs emphasized that their limited resources meant only some of their beneficiaries had received such support, and many had been left without.

Part II - Disability Inclusion in the COVID-19 Response

Montenegro does not have a comprehensive strategy plan for dealing with humanitarian crises. There is inadequate coordination by public authorities in crisis response. There is no prioritization of marginalized groups and the needs of persons with disabilities are not assessed. DPOs and OPDs reported that they did not receive government support to assist their members but had to rely on international donors' support.

Respondents reported that response measures were hampered by limited coordination among institutions (e.g. social and health care system, social system and the police). This is illustrated with an example of a family of a person with disability living in the north and receiving therapy in the Clinical Centre in Podgorica who was left without medical

or any other transportation. As a result, the family had to borrow money to pay for a taxi ride both ways because there is a €50 euro difference between the actual fare and the refund from the Health Insurance Fund.

Participation in decision-making

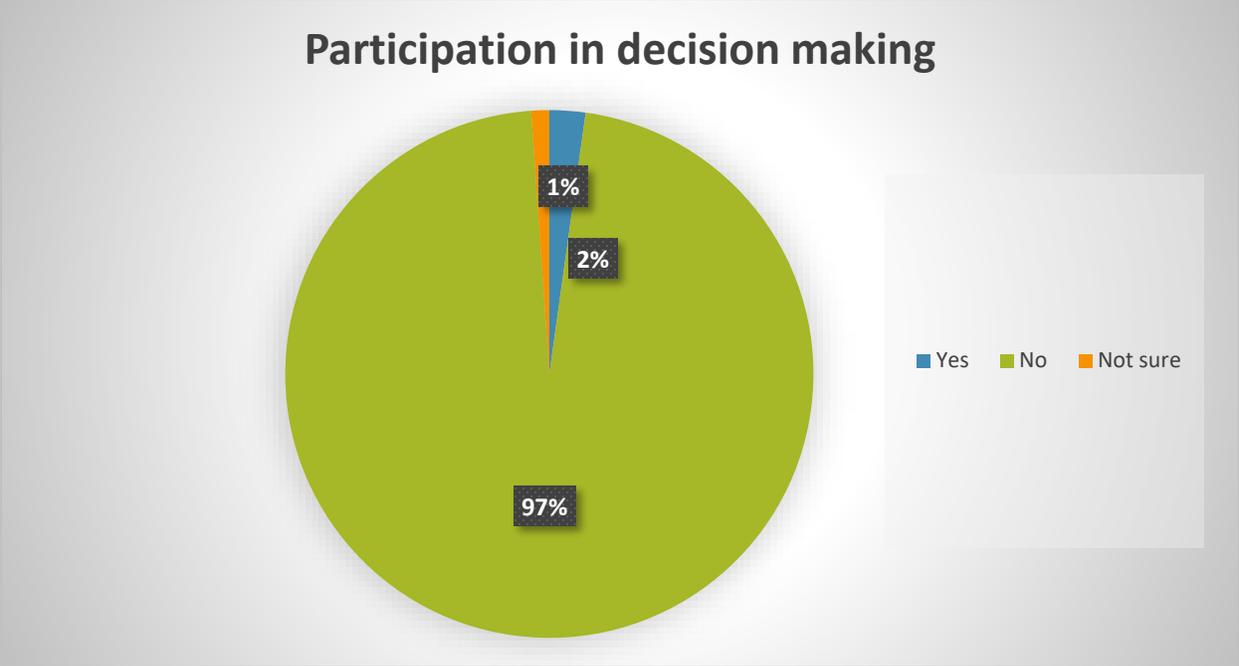
Since the outbreak of the epidemic in Montenegro in March 2020, no institutional mechanism has been set up in the country for cooperation between the State and DPOs and OPDs. The Government established a National Coordinating Body for Communicable Diseases, composed of representatives of public authorities only. In June 2020, the former Government adopted the Decision on the establishment of the Council for Care for Persons with Disabilities, but the Council was never formally established. Therefore, DPOs and OPDs had no formal opportunity to participate in decision-making in the COVID-19 response and recovery, despite their numerous appeals to be included. Disability rights activists called for consultations, if not through formal bodies, on decisions relevant to persons with disabilities, new virus containment measures or support measures to mitigate negative effects of the crisis.

DPOs and OPDs report that in situations when they were included in decision-making processes, this never happened at the initiative of the institutions, but rather of DPOs and OPDs themselves. In their first address to the line institutions, AYDM and Union of the Blind of Montenegro requested prior impact assessment of the measures on persons with disabilities and exemptions from strict restrictions, accessibility of information and communication, provision of PPE and work equipment for persons with disabilities service providers, coordination among institutions in assessing the cost of living of persons with disabilities and securing funds to cover such costs, as well inclusive education for children with disabilities, equipment and other means where needed.⁴ Only one recommendation was partly implemented by the authorities: sign language interpretation was provided during some press conferences of the National Coordination Body.

Overall, 96.7% of respondents with disabilities (84 youth with disabilities) who took part in the survey reported they did not participate in decision-making during the COVID-19 epidemic. Only one person in the survey sample was involved in decision-making, and that is a person with a disability employed in an institution. Only 8.9% respondents (youth with disabilities) had suggested some support measures for persons with disabilities. They took part in interviews by the media, or made appeals to the Red Cross, employers, and various government bodies and institutions.

⁴ The initiative was sent on 17 March 2020.

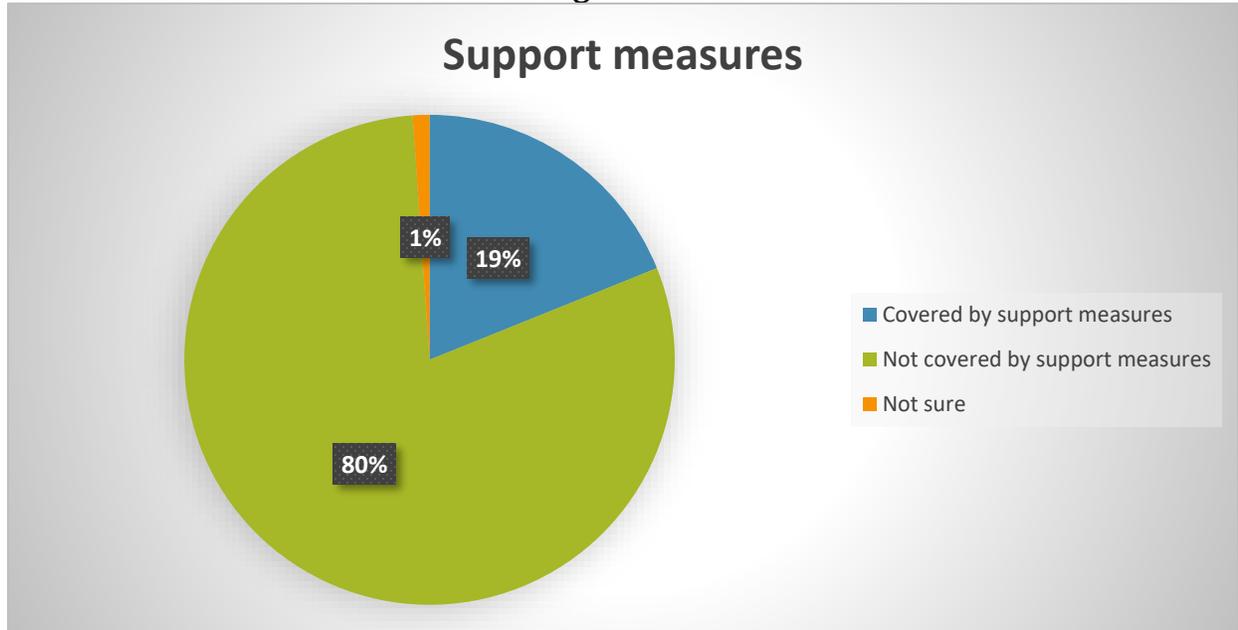
Chart 4. Answers to the question: “Have you been included or had an opportunity to participate in decision making processes about COVID-19 related support measures?”



Disability inclusion in post-crisis support measures (recovery)

Overall, respondents feel that persons with disabilities had not been included in recovery measures at all, and that they had been excluded by the Government. The support that was accessible was that provided by the NGO sector. 80% of respondents (72 respondents of which 63 are youth with disabilities) were not covered by any state support measures intended to mitigate the negative impact or assist in the recovery from COVID-19, while 18.9% (17 of which nine are youth with disabilities) received some form of assistance and support (one-off financial support, food and PPE), including from humanitarian organisations.

Chart 5. Answers to the question “Have you been covered by some support measures during COVID-19?”



Some persons with disabilities who had sought assistance and support from NGOs for the first time due to the epidemic reported it was positive that NGOs continued providing support even for aspects not related to COVID-19.

Some respondents reported that even if they wanted to seek assistance, they had no idea who to turn to. Although during the outbreak there were significant donations, primarily for virus containment, mitigation of effects of the crisis, medical supplies and PPE, this support which mainly came through international cooperation, was not disability inclusive.

12.2% of respondents (11 of which five are youth with disabilities) received some sort of humanitarian aid, while some among those who had not received humanitarian aid reported they knew other people who had received aid from the municipality (which shows the criteria were not clear or transparent).

During the epidemic, MLSW, through CSWs, provided 4458 beneficiaries with one-time financial assistance totalling €320,620.00. As there is no segregated data, however, it is unknown how many youth with disabilities were included.

MLSW reports it proposed and took all decisions in cooperation with NCB and IPH and that all proposed measures included, but were not limited to, persons with disabilities. There is no data on how many persons with disabilities were covered by these measures.

Overall conclusion

According to this survey with youth with disabilities as well as DPOs and other stakeholders engaged in disability rights in Montenegro, the COVID-19 pandemic has had a disproportionately negative impact on all persons with disabilities, including youth. Those surveyed reported feeling further marginalised in the response measures taken to reduce the spread of infection as these were developed without consulting and in a non-inclusive

manner. The crisis has negatively impacted on youth with disabilities' economic security, their access to health care and assistive devices, as well as their access to information and education. Respondents to the survey stressed that the marginalisation and the discriminatory barriers that they face existed already before the pandemic, however these barriers were greatly exacerbated during the crisis leaving them further behind.

The lack of understanding of the scale and impact (and therefore the needs) of the crisis on persons with disabilities, including youth, in Montenegro has emphasised again the urgent need for the state to develop a comprehensive register of persons with disabilities. Such data is essential not only to build back better but also for better preparedness for potential future pandemics and other humanitarian emergencies.

RECOMMENDATIONS:

DPOs and OPDs feel that the adverse impact of the pandemic on persons with disabilities would have been significantly lower had the responses been steered by the State's obligation under the CRPD. This would include meaningful consultation with DPOs and persons with disabilities who throughout the crisis have been lobbying for various measures to ensure the response was disability-inclusive. Most of these calls by DPOs have been ignored by the authorities.

A consistent call of DPOs and OPDs and a requirement of the CRPD is the development of a register of persons with disabilities, which should include not only demographic data but also specific disability-related data and disability-related living expenses. A key recommendation from this study is that the authorities urgently begin to collect this data. The registry would ensure more adequate needs assessment and planning, and a fairer and inclusive distribution of support.

The second important precondition for negative impact reduction relates to accessibility of the physical environment, institutions, information (including in the media and produced by media), ICT, communication, transport and services, also including diversity of services, both public and community-based, recognition of sign language as a language in the official use, among other things.

In addition, improved quality and standards of health care services and protocols for the treatment of persons with disabilities would reduce the additional negative health impact during the crisis. Inclusive social protection services and targeted measures to reduce poverty within the disability community, and their regular and adequate financing, would reduce the negative social impact and risk of marginalization during the crisis.

Key recommendations for the period before and during the crisis include the establishment of a national institutional framework for cooperation between the state and DPOs – a consultative body for persons with disabilities' rights, and inclusion of persons with disabilities and their representative organizations in COVID-19 decision-making, in particular in proposing and adopting protection measures, but also crisis recovery measures.

The Government should, on the basis of research and impact analysis, develop a recovery strategy with targeted support measures for persons with disabilities and their families with more financial support at the national and local level. The measures should reflect the diversity of disability and correct the under inclusive understanding of disability that sets the threshold for accessing existing support – leaving many persons with unrecognized impairments without support. Financial support should include paid leave for persons with disabilities and their family members, increasing the amount of disability benefits, but also additional payments, including especially covering disability-related extra costs. Crucially, the application process for these supports should be easily accessible and at no cost to the person seeking support and responded to in an efficient and timely manner.

It is also necessary to develop programs and support measures related to habilitation, rehabilitation, and support programs for acquisition of greater employability, personal development and self-employment capacities and competencies needed in a modern society (including IT and digital transformation). Lastly, all economic recovery programs should be disability-inclusive.