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THE COVID-19 PANDEMIC THROUGH THE PRISM OF THE RIGHTS OF PEOPLE WITH DISABILITIES AND THE OBLIGATIONS OF THE COUNTRY IN THE FIELD OF SOCIAL PROTECTION AND LABOUR MARKET

Abstract

The crisis caused by the coronavirus pandemic managed to intensify and in a very short time it brought to the surface the problems the marginalized citizens faced with in the society, which include people with disabilities, as well as their caregivers. Taking into consideration the continuing marginalization of people with disabilities in North Macedonia, with the support of the Westminster Foundation for Democracy, the authors of this paper conducted a brief survey on the Impact of the Covid-19 Crisis on People with Disabilities in North Macedonia¹, published in May, 2021. The survey covered a period of one year, i.e., from the beginning of the pandemic with the declaration of the state of emergency. This paper is based on the conducted survey, and the aim is to present the situation that people with disabilities and their caregivers experienced as a result of the measures and policies that

were adopted during the pandemic, and resulting from the pandemic itself, with a special focus on the situation in the field of social protection and the labour market. The challenges faced by people with disabilities that existed long before the pandemic, such as increasingly present stereotypes and prejudices, inaccessible infrastructure, discriminatory practices in the education system and the labour market, but also non-accountable institutions, were significantly emphasized as a result of the inadequate coping with the pandemic caused by Covid-19. This only confirmed the unfavourable position of people with disabilities, but also of their caregivers, in terms of opportunities to ensure a quality life. The challenges faced by people with disabilities in terms of access to social protection and their inclusion in the labour market were particularly difficult, considering that the restrictive measures for prevention and protection from Covid-19 were not in line with the needs, i.e., the possibilities of people with disabilities.

¹ The survey is available at: <https://mhc.org.mk/publicationsanalyzes/vlijanieto-na-kovid-19-krizata-vrz-licata-so-poprechenost-vo-severna-makedonija/>.

Key words: people with disabilities, social protection, labour market; Covid-19;

INTRODUCTION

Although the pandemic caused by Covid-19² affected everyone, the measures for coping with the pandemic and the consequences caused by their (in) appropriateness, differently and unequally reflected on different categories of citizens. Hence, the coronavirus crisis has only intensified and brought to the surface the problems that people with disabilities, their parents and caregivers face on a daily basis.

Some of the challenges for people with disabilities, which existed long before the pandemic, refer to the increasingly present stereotypes and prejudices in our society, the inaccessible infrastructure, the discriminatory practices in the education system and the labour market, but also the non-accountable institutions.

One indicator of the obstacles in the daily functioning of people with disabilities before the pandemic, is the data that they belong to the groups of citizens whose rights are often violated and who face discrimination. The mentioned challenges for people with disabilities were significantly emphasized by the inadequate coping with the Covid-19 pandemic.

Hence, considering the continuing marginalization of people with disabilities in this country, with the support of the Westminster Foundation for Democracy, in early 2021 the authors conducted a brief survey on the impact of the pandemic crisis on people with disabilities and their caregivers,³ from the onset of the pandemic, i.e., from the Declaration of the State of Emergency. In order to mitigate the negative implications caused by the coronavirus pandemic on the daily functioning of people with disabilities, the analysis aimed to create a better picture of the situation that people with disabilities are their caregivers experienced, but also to provide specific guidelines and recommendations that will help in the further creation of appropriate measures and policies that directly and indirectly affect people with disabilities.

The research focused on several areas that were identified as the most important factors for the well-being of people with disabilities, as follows: involvement in the processes of creating measures, access to information, healthcare, social protection, education, work and employment, costs, accessibility, transport and mobility. Hence, this paper is based on the conducted survey, and the goal is to show the impact of the pandemic on people with disabilities

² The disease caused by the coronavirus SARS-COV-2.

³ Caregivers of persons with disabilities include parents, guardians, carers, personal assistants of children and persons with disabilities.

and their caregivers, with a special focus on the situation in the field of social protection and labour market. Part of the results of the conducted research will be presented here, which refer to these two areas, which the authors found by applying several methods for primary and secondary data collection. Namely, in order to master the subject of research, the existing literature, international standards and the national legal framework relevant for the protection of people with disabilities were analyzed, with a special focus on the regulations with legal force that were adopted during the state of emergency; the data obtained from the conducted questionnaires with relevant stakeholders were analyzed, including institutions, organizations of people with disabilities and organizations for people with disabilities and international organizations;⁴ the survey questionnaires conducted with people with disabilities and caregivers of people with disabilities were analyzed;⁵ and a verification meeting was held on the initial conclusions and

recommendations from the conducted research.⁶

One of the main conclusions of the authors is the reaffirmation of the marginalized position of people with disabilities and their caregivers, which was particularly expressed during the pandemic. The research only confirmed the unfavorable position of people with disabilities, but also of their caregivers, in terms of opportunities for providing quality life and daily functioning without barriers of different nature. The challenges faced by people with disabilities in terms of access to social protection and their inclusion in the labour market were particularly difficult, given that the restrictive measures for prevention and protection from Covid-19 were not in line with the needs, i.e., the possibilities of people with disabilities.

People with disabilities and the pandemic

Although some progress has been made regarding the improvement of the legislation in North Macedonia, in order to harmonize it with the international regulations, including the European legislation, the laws, bylaws and policies related to people with disabilities still have not been sufficiently harmonized

⁴ The answer to the questionnaire intended for state institutions was submitted only by the Ministry of Education and Science, while the questionnaire intended for organizations and other stakeholders was answered by five domestic citizens' associations, one international organization and two organizational units at the Faculty of Philosophy within Ss. Cyril and Methodius University in Skopje.

⁵ A random sample was used, i.e., a suitable sample. The questionnaire was available online and by phone, and was completed by a total of 218 respondents, of which 59 persons with disabilities and 159 caregivers of persons with disabilities.

⁶ The verification meeting was held on March 3, 2021 in the form of a round table intended for organizations, but also for individuals working in the field of persons with disabilities and caregivers of persons with disabilities. The round table was held online through the ZOOM platform and a total of 17 participants took part.

with the Convention on the Rights of People with Disabilities, as suggested by the recommendations of the Committee on the Rights of People with Disabilities (2018). This year's report of the European Commission on the progress of North Macedonia once again confirmed that the progress that has been achieved in terms of the rights of people with disabilities in the country is insignificant (European Commission, 2021). According to the report, people with disabilities, who were one of the most vulnerable and affected groups of citizens during the Covid-19 pandemic, still face significant direct and indirect discrimination, primarily due to inaccessible infrastructure, lack of information and services, discriminatory attitudes in the society and social exclusion. The lack of comprehensive statistics on people with disabilities further complicates the process of creating appropriate policies and measures that will respond to the specific needs of this category of citizens.

The warnings of the negative effects on the well-being of vulnerable categories of citizens, including people with disabilities, which may be a consequence of the Covid-19 virus, were addressed at the very beginning of the pandemic. Thus, the World Health Organization suggested the increased risk of infection with the virus in people with disabilities, primarily as a result of the existing barriers to the implementation of basic hygiene measures, difficulties in maintaining distance due to the need for additional

support or living in an institution, the need for physical contact as a way of receiving information from the environment, and previous health problems (WHO, 2020). The situation that people with disabilities faced as a direct result of the pandemic is only an indicator of the already existing weaknesses of the public service system and the unequal access to these services for specific vulnerable categories (UN, 2020).

The people with disabilities in this country are generally insufficiently involved in the policy-making processes, which was especially evident during the pandemic. The data from the research conducted by the authors confirmed that neither people with disabilities, nor civil society organizations operating in this field, were involved in the adoption of measures and policies for protection and coping with the consequences of the virus, therefore they were not in line with their specific needs, as well as the needs of their caregivers. This is supported by the fact that out of a total of 250 regulations with legal force that were adopted during the state of emergency, only two regulations explicitly mention people with disabilities. In addition, only after reactions and requests were submitted by the associations, changes to the measures were made, however after their previous adoption by the Government.

The measures introduced by the Government for the prevention and protection from the Covid-19 virus caused difficulties in the performance

of daily works for most people with disabilities and their caregivers. Many of these difficulties referred to limited socialization and limited movement as a result of movement restrictions, including the introduction of curfew. For some people with disabilities, the adherence to the measures of protection against the virus, such as maintaining physical distance, wearing a mask, and avoiding grouping, created a serious problem for their daily functioning, considering that some people, for example, cannot wear a mask due to respiratory problems, they have to move with a companion, etc.

People with disabilities and their caregivers face discrimination and violations of their rights on a daily basis. According to the data from the *Report on provided legal aid* by the Helsinki Committee for Human Rights for the period August 2016 January - 2018, people with disabilities include some of the groups of citizens whose rights are violated and most frequently face discrimination (Jadrovski et al, 2018). One of the most common problems that people with disabilities and their caregivers encounter is the inaccessible infrastructure, starting from the institutions themselves, as well as the streets, sidewalks, parking lots and public buildings. Inaccessibility is still a serious problem, even in case when the person moves with a companion (Jovanovska, 2020). Thus, even during the pandemic, people with disabilities and their caregivers reported that they

faced difficulties in exercising their rights during the pandemic, whereby very few people requested assistance, usually in social welfare centers, and a small portion requested assistance from civil society organizations. Only a small part of the people received the requested assistance, i.e., exercised the requested rights.

The limited or hindered access to institutions that people with disabilities face on a daily basis was significantly expressed during the pandemic, primarily as a result of the reduced functioning of the institutions and the limited transportation during this period. Some of the people were not able to use public transport because they were unable to wear a mask and fully comply with the measures for protection against the virus. Only a small number of the institutions are fully accessible to people with disabilities, and this also refers to the accessibility of their information.

Since the beginning of the pandemic, certain adjustments have been made regarding the provision of specific health services, primarily related to the extension of the validity of the required documentation to exercise a right to health care. However, a large number of the respondents included in this study still encountered difficulties in obtaining health services and healthcare, including the inaccessibility of testing centers. In addition to the dissatisfaction of people with disabilities and their caregivers regarding the professionalism of health professionals, they also had to deal with

crowds and queues at health facilities and pharmacies, which further exposed them to risk of contracting the virus.

The pandemic inevitably affected the financial situation of people with disabilities, while significantly increasing the costs related to health prevention, intended for hygiene products and medicines. The people with disabilities faced additional problems when they had to purchase medicines that are not included in the positive list of medicines of the Health Insurance Fund, same as the people who previously procured the necessary therapy abroad, so with the closing of the borders and the movement restrictions, they were no longer able to provide their therapy.

The impact of the pandemic did not spare the process of deinstitutionalization of the institutions for people with disabilities. Although this process has gained momentum in the last two years before the commencement of the pandemic, aimed at ensuring a dignified and quality life and social inclusion of people with disabilities, the pandemic has put a halt to the implementation of the process, especially in terms of establishing and development of community services.

Social protection

Regulations in the field of social protection

The Law on Social Protection is the general law in this field that regulates the institutional and non-institutional

protection of people with disabilities and the financial assistance. During the state of emergency, on April 4, 2020, the *Regulation with legal force for the application of the Law on Social Protection during the state of emergency* was adopted.⁷ This Regulation did not contain provisions for the smooth exercise of the rights of people with disabilities in pandemic conditions. It only regulated the procedure for obtaining the minimum guaranteed assistance for households without material protection for April and May, 2020 (Article 2). In addition, a monetary supplement was provided to cover part of the costs for household energy consumption for April and May, 2020 (Article 3).

Even with the amendments to this Regulation, the people with disabilities and the exercise of their right to monetary compensation were explicitly mentioned. The amendments of April 24, 2020 for the first time more specifically regulated the issue of this right to social protection used by people with disabilities.⁸ The exercise of the right to disability compensation was extended for the entire duration of the state of emergency and two months after its termination. The extension was intended for people with disabilities who exercise this right based on a council

⁷ Government of the Republic of North Macedonia "Official Gazette of the Republic of North Macedonia" no. 89 dated 3.4.2020

⁸ Government of the Republic of North Macedonia "Official Gazette of the Republic of North Macedonia" no. 108 dated 24.4.2020

opinion, and a check-up examination was recommended during the state of emergency.

for exercising social protection rights, in pandemic conditions and in conditions of general institutional stagnation. People

Government of the Republic of North Macedonia	3 April 2020	<i>Regulation with legal force for application of the Law on Social Protection during a state of emergency</i>	“Official Gazette of the Republic of North Macedonia” no.89 dated 03.04.2020
Government of the Republic of North Macedonia	24 April 2020	<i>The regulation with legal force for amending the Regulation with legal force for application of the Law on Social Protection during a state of emergency</i>	“Official Gazette of the Republic of North Macedonia” no.108 dated 24.04.2020

Analysis of the field data

According to the latest available data from the State Statistical Office, in 2019, 30.271 adults⁹ with a disability are registered as social protection beneficiaries. This number includes 12.908 women with a disability. In regard to the type of disability, 3.228 are people with impaired vision, 3.098 are people with impaired hearing, 16.125 are people with physical disabilities, 4.016 are people with mental disabilities and 3.804 are people with combined disabilities (State Statistical Office, 2019). The data from the conducted research of the authors, collected through interviews with relevant stakeholders in the field of social protection and with respondents with disabilities and their caregivers, are an indicator of the difficult situation that these people go through during the pandemic.

The interviewed stakeholders locate the problem in the renewal of the documents

with disabilities and their caregivers only confirmed the data obtained from the interviews with the stakeholders. Namely, as the most common problem, they indicated the need to constantly prove the disability by updating the documentation, so that they can use certain social protection rights. In this regard, 23.7 percent of the respondents in the survey believe that the simplification of the procedures by submitting and renewing the documentation, would significantly facilitate their acquisition and/or the enjoyment of a right to social protection.

A typical occurrence in such circumstances is the expression of the negative consequences of underdeveloped support services. This has been particularly observable in people with disabilities who live alone or with elderly parents or guardians. The view that social protection institutions are inaccessible and non-responsive had prevailed among people with disabilities long before the onset of the pandemic

⁹ At 26 to 65 years of age.

(Kochoska et al. 2018). The crisis has only significantly increased the risk that some of the beneficiaries of social rights will lose the necessary benefits for a certain period of time. The effect of the crisis on people with disabilities is evidenced by 52.3 percent of the respondents who have faced difficulties in exercising their rights during this period. On the other hand, 30% of the respondents encountered obstacles when receiving social protection services. Of these, 49.2 percent indicated problems arising from the closure of day care centers, 46 percent indicated problems in obtaining financial assistance, and 44.4 percent of the respondents generally experienced difficulty when accessing services.

It is estimated that approximately 6.400 to 9.600 people with disabilities from 18 to 65 years of age do not have contact with social services, or between 1/3 and 1/2 of the total number of registered people (MLSP, 2018). Hence, the fact that only 38.6 percent of the respondents requested assistance during the pandemic, is a defeating fact, considering that more than half of the total number of respondents had difficulties in exercising their rights. Moreover, 43.9 percent of the people who requested help said that they mostly addressed directly to the centers for social work, and a smaller part or 24.6 percent communicated with civil society organizations. Only one third of them, i.e., 36.8 percent received the requested assistance. Hence, 28.9 percent of the respondents logically

follow this, emphasizing the need for greater professionalism of the employees, including greater organization and functionality of the administration.

The numerous administrative obstacles and the unharmonized application of the legal provisions by the competent institutions hinder/make impossible the exercise of the rights and use of social services (Jovanovska, 2020). The restrictive interpretation and application of the already narrowly defined framework for social protection in these conditions additionally contributes to the increase of social risk and poverty in some people with disabilities. The confirmation thereof are 76.1 percent of the survey participants who faced rising costs during the crisis, and more than half of them (55.4 percent) still fail to overcome cost problems. 82.5 percent of the respondents found it difficult to bear the cost for hygiene and virus protection, 66.9 percent - increased costs for drugs, 56.6 percent - the cost of food, 41.6 percent - the cost of transport, and 39, 8 percent - the cost of housing.

Transport-related costs make visible the gap and the differences between people with disabilities and the other citizens, but also between people with disabilities themselves. The inaccessibility of transport has further increased the cost of individual transport (for example, taxi). Moreover, organized public transport is available only in larger cities, which means that the past period has been particularly restrictive for the movement of people

with disabilities from the rural areas. Most of the respondents who faced it increased costs for transportation, or 28.3 percent, point out that the abolition of organized transportation to day care centers is the major problem. In addition, 18.5 percent stated they faced difficulties while using the already reduced public transport, due to the risk of the virus and the impossibility to properly comply with the safeguards.¹⁰

Moreover, the testimonies of the interviewed stakeholders show of a large number of people with disabilities who did not meet the requirements for financial support, despite the fact that due to the crisis they lost their income (or their income has reduced), or they lost their jobs. In this regard, it is especially important to point out that the country acted contrary to the obligations stipulated with the Convention on the Rights of People with Disabilities and the principles that the country is bound to respect. In conditions of one of the biggest health and economic crises, the state did not pay attention to the negative impacts of poverty on people with disabilities.¹¹

Conclusions and recommendations

The impossibility to use the services of day care centers was one of the key

problems for people with disabilities which arose from the analysis of the collected data. Although the day care centers were open in the meantime, they operated with a limited capacity, and the organized transportation to and from the day care centers was limited. Hence, the recommendation to enable day care centers to operate with full capacities inevitably arose by adopting appropriate protocols for their operation. Thereby, unobstructed organization of regular transportation for the users is necessary, which for many has proved to be extremely important in times of a pandemic, and it contributes to the efforts to control the risk of poverty.

The lack of professionalism of some of the professionals employed in the centers for social work and the lack of organization of the administration for the provision of social protection services are the main factor for limiting the enjoyment of the rights of people with disabilities on an equal basis with others. Therefore, it is particularly important to comply with the codes of ethics for working and maintaining a high level of professionalism in communicating with people with disabilities in accordance with their specific needs and circumstances. All of this would prevent people with disabilities from feeling discouraged when using the available services.

The very nature of the pandemic has significantly encumbered the collection and renewal of documents to prove the disability, which in some cases has led

¹⁰ In this regard, the respondents pointed out problems when using a protective mask, blurring of glasses, breathing problems, inability to lip-read, as well as problems that occur when explaining the need to wear a mask to some people with disabilities.

¹¹ Convention on the Rights of Persons with Disabilities. Preamble, paragraph p.

Government of the Republic of North Macedonia	April 7, 2020	<i>Regulation with legal force for application of the provisions of the Law on Employment of Disabled People During a State of Emergency</i>	“Official Gazette of the Republic of North Macedonia” no. 94 dated 7.4.2020
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to the loss of social protection rights. In this regard, it is necessary to adopt and/or properly implement the protocols that will help to overcome the problems with the collection and renewal of the documents for exercising social protection rights. The simplification of the procedures, as well as the introduction of the possibility for electronic renewal and submission of the complete documentation, would significantly facilitate the use of the right to disability compensation.

Furthermore, the challenges that lead to increased social risk and poverty among people with disabilities can be overcome only by developing the support services they use. This will have a particularly positive effect on people with disabilities who live alone or with older people who take care of them, and who have faced a lack of appropriate support in their home.

The labour markets

Regulations in the field of the labour market

Having in mind the complexity and scope of this field, 16 regulations with legal force were adopted, which regulated various aspects of the labor market. In this way, labor relations and labor rights

were regulated, as well as state financial assistance and support for people at social risk and state financial assistance for the affected companies in order to subsidize salaries and compulsory social insurance contributions. The issues that were regulated with the regulations/decrees directly or indirectly (through their caregivers) affect the people with disabilities. Still, they were excluded from the measure of subsidizing salaries and contributions, and also, they were not covered by the financial support of citizens and low-income employees, young people and health professionals by issuing a domestic payment card.

The regulation with legal force for application of the provisions of the Law on Employment of Disabled People During a State of Emergency,¹² which explicitly mentions people with disabilities, set out and extended the deadlines for exercising the rights and obligations under the Law on Employment of Disabled People, for the duration of the state of emergency. Briefly, this Regulation provided that the deadlines cease to run for the duration of the state of emergency and continue after the expiration of the time for which the

¹² Government of the Republic of North Macedonia “Official Gazette of the Republic of North Macedonia” no. 94 dated 7.4.2020

state of emergency has been declared, but only for the remaining days (Article 2).

Analysis of the field data

The pandemic, and especially the inadequate measures to cope with the crisis, have imposed a number of economic challenges with significant negative effects on the labor market. Hence, the large number of layoffs, the reduction and non-payment of their salaries, the absence of health insurance for workers during the greatest health crisis in recent years, are just some of the problems that give the pandemic the character of a labour crisis (Petkovska, 2020). In the period from March to June alone, 799 workers who lost their jobs reported this to the Helsinki Committee for Human Rights (ibid), while the Employment Agency registered 43.086 people who lost their jobs since the commencement of the crisis in March 2020 (ESA, 2021).¹³

The latest official data on people with disabilities and their participation in the labour market recorded by the State Statistical Office were recorded in

2017. Namely, this year, the working age population included 1.679.935 people, of which 56.8 percent are active and registered on the labour market, and 43 percent are inactive or out of the labour market. Of a total of 725.723 inactive participants on the labour market, 59.701 are people with some form of disability. On the other hand, 31.781 people cannot participate in the labour market despite being able to work, due to lack of home support services. This means that they are forced to stay at home and take care of their relatives or close people with disabilities (State Statistical Office, 2017).

More than half of the surveyed people with disabilities and their caregivers are employed, that is, 57.5 percent, 32 percent are unemployed, while only a small portion includes pension beneficiaries (7.3 percent). People with disabilities were largely covered by layoffs as workers with chronic health conditions. A significant part of the people with disabilities were left without economic benefits precisely because of the measures not to go to work, so in the absence of adequate financial support they were directly exposed to poverty and lack of any social security (Center for Research and Policy Making, 2020). One-third or 29.4 percent of the respondents experienced workplace difficulties during the pandemic, and almost half of them (48.4 per cent) were related to absence from work as a way to protect from the virus and care for another person at home.

¹³ The Employment Service Agency as late as in June started to keep separate statistics on the inflow of persons who have acquired the status of unemployed persons, for whom the withdrawal from compulsory social insurance was registered in the period after 11.3.2020. The total number of unemployed persons, starting from March 2021, is presented here. The number of unemployed persons for March, April and May, for which Employment Service Agency did not keep separate statistics in regard to the crisis, is 21.838 persons.

However, the people with disabilities and their caregivers were not immune to the wave of layoffs and job losses that directly affected workers. Namely, one of the interviewed associations registered several cases where people with disabilities were fired due to reduced workload with their employers. Another actor notes that the problem originates from the fact that the reduced workload and the replacement of part of the production activities leads to the liquidation of the protection companies, where people with disabilities are usually employed. In this regard, the Association of Protection Companies of Macedonia expects a large number of protection companies to be liquidated during the pandemic, which would de facto leave people with disabilities jobless. People with disabilities in rural areas also faced a potential lack of work engagement. Namely, the people who are temporarily engaged as seasonal workers fear that they will not have enough work due to the reduced production and export of products abroad.

Conclusions and recommendations

Long before the pandemic, people with disabilities faced limited entry into the labour market, however the crisis significantly increased and deepened this risk, including the risk of losing their

jobs. Structural shortcomings are still observable in the labour market, which hinder potential growth and development. This is also observed by the European Commission and it points out that women, youth, people with disabilities and low-skilled people in our country are most exposed to unemployment (European Commission, 2021).

Most of the respondents faced work difficulties arising from absence from work due to care for a person with a disability at home, and the situation of people with disabilities in rural areas is also concerning, who are left without any support for the entire duration of the pandemic. Hence, one of the recommendations that emerged in this regard again refers to the need to enable day care centers to operate with full capacities, including organized transport of users, as well as the provision of appropriate protocols for the operation of kindergardens and day care in conditions of repeated restrictions, in order to reduce the risk of losing the jobs of caregivers of people with disabilities. At the same time, what is necessary in the process of creating new measures is to focus on the mitigation of the consequences that we are yet to face, given that the pandemic is still present and we will feel the consequences of the pandemic in the future as well.

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