

The research priorities in disability studies related to COVID-19

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The novel coronavirus disease (COVID-19) pandemic crisis presents a considerable challenge to the population of people living with disabilities. The main purpose of this paper was to identify the emerging research areas in disability studies related to COVID-19 in order to set out the immediate priorities and longer-term strategies for science research and evidence-based practises. Prioritized topics in public health and general health-related topics were discussed, including cognitive sequelae and various neurological manifestations in COVID-19 survivors with disabilities, new surveillance or data collection systems, strategies of improving the health protection measures for people living with disabilities, and the question of equity in access to medical care. Service disruptions have highlighted the importance of implementation of the biopsychosocial model and evidence-based service decisions and that future research should be directed towards the problems of adaptation and management of outpatient and inpatient clinical work, pandemic-specific information needs and standardization of the best-practice rehabilitation protocols. Geographic information system methods or a spatial analysis was recommended. Particular attention was called to the research and innovative approaches to telehealth or telemedicine in therapeutic, rehabilitation, assessment and follow-up purposes, as well as the raising ethical issues related to using disability as a factor in denying life-saving treatment. High-quality research standards, multidisciplinary and intersectoral approach with a global perspective and international research results comparisons were suggested. The upcoming findings of disability studies would certainly improve the society's ability to adjust and prepare for a re-emergence of COVID-19.

Keywords: COVID-19, coronavirus, disability, people with disabilities, research, Serbia

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Introduction

On 11th March 2020, the World Health Organization (WHO) has declared the novel coronavirus disease (COVID-19) outbreak a global pandemic (WHO, 2020d). The following day, a four-pronged strategy was presented: 1) prepare and be ready; 2) detect, prevent and treat; 3) reduce and suppress transmission; 4) innovate and improve, with an emphasis on the necessity of a balance between health protections, prevention of economic and social disruption, and respect for human rights (WHO, 2020e).

COVID-19 has received worldwide public and government attention after it was reported to the WHO on 31 December 2019 (Mohammadi et al., 2020). Since then, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) has a profound effect on the health and health management, economy, and socio-economic framework of the global society (Haleem et al., 2020). Most of the attention, especially at the very beginning of the crisis, was dedicated to comorbidities in the prevention and treatment (Cucinotta & Vanelli, 2020; Mohammadi et al., 2020). Immediate action implied that the residents, including those with underlying comorbidities, were obliged to take all preventative measures not to contract the virus, like physical, or social, distancing or self-isolation (Kuper et al., 2020; Pal & Bhadada, 2020). As indicated, older people, people experiencing social disadvantage and marginalization and people living with or affected by non-communicable diseases or underlying illness are at the increased risk of exposure, serious complications, and death caused by COVID-19 (Cucinotta & Vanelli, 2020; Mesa Vieira et al., 2020; Pal & Bhadada, 2020; UNICEF, 2020; WHO, 2020c; Yang et al., 2020).

In other words, to reduce the transmission of the virus, millions of people worldwide have been put on lockdown. According to some estimates, a third of the world population was on some form of a coronavirus lockdown, active restriction or control by governments (Buchholz, 2020). In some cases, physical, or social, distancing was mandatory at the national level with travel restrictions (Habibi et al., 2020). However, unique concerns of people living with disabilities and their families are often overlooked, forgotten or considerably neglected during such challenging times, as shown in the study on persons with spinal cord injury (O'Connell et al., 2020). It is believed that COVID-19 pandemic crisis presents a more considerable challenge to the population of people living with disabilities, considering the position and

vulnerability (Jalali et al., 2020). As a reminder, more than 16% of the world's population live with some form of disability (WHO, 2011). Comprehensive research is needed to determine the effect of physical, or social, distancing and isolation on wellbeing with clear evidence-based recommendations for future outbreaks. In the context of disability studies, well-being and quality of life are considered at the individual and family level.

Current limitations and gaps in the knowledge of SARS-CoV-2 and its direct and indirect effects require extensive research in several major research areas. Among other, major research areas impacted by COVID-19 include medicine, economy and global trade, information and advance technologies, environment and sustainability, education, learning and capacity building, psychiatric and psychological issues (Haleem et al., 2020). As highlighted, medical research areas involve the development of medicines, vaccines and health care equipment for the prevention and treatment of COVID-19, but also the development of risk resilient medical supply chains. Public health and policy research focuses on the ability of the current infrastructure to manage public health issues and to provide medical care to all in need. Psychological issues cover a whole range of topics, from an acute need for counselling to the stigma of disease and mechanisms to overcome them, followed by the mental health of the people after lockdown.

Given that the literature concerning COVID-19 is emerging, the effect of the current crisis is noticeable in the change of focus and intensification of scientific research. At the time of the drafting of this manuscript, our simple search for "COVID-19" yielded more than 18,000 results on PubMed, nearly 13,000 on Scopus, 5,353 in Web of Science and more than 30,000 through Google Scholar.

Acute or long-term consequences of lockdown and social isolation imposed during the COVID-19 pandemics are yet to be explored in full. To inform management of these consequences, to guide policymakers and provide clear evidence-based recommendations for future outbreaks, it is necessary to acknowledge that physical, or social, distancing, loss of employment or working from home have unexpectedly interrupted many daily routines and social opportunities important to health, physical and psychological wellbeing of people with disabilities and their families. For that reason, we need to identify new research problems and cross-cutting research themes to set out the immediate priorities and longer-term strategies for science research and evidence-based practises. It is reasonable

to expect that many academic research areas within disability studies are or will be impacted by COVID-19, as well.

The main purpose of this paper is to identify the emerging research areas in disability studies related to COVID-19. The findings may assist in raising awareness of the complexity of consequences and provide initial ideas and directions for future research in this area.

COVID-19 inclusive health research framework

Some authors explain a higher risk of virus infection, in general, in people with disabilities by reminding on the overpopulation in residential care settings and objective difficulties to provide adequate physical, or social, distance (Safta-Zecheria, 2020; Tummers et al., 2020). Also, residents often depend on physical contact with a caretaker, that is, employees of residential care institutions in daily life activities (Safta-Zecheria, 2020; Tummers et al., 2020). Five principal topics that arose in research related to people with disability and COVID-19 pandemic are the following: mental health, viral diseases, diagnoses and treatments, maternal care and paediatrics, and genetics (Tummers et al., 2020). Reasonable concern was expressed regarding cognitive sequelae and various neurological manifestations in survivors of severe and critical COVID-19 (Carda et al., 2020; Politi et al., 2020).

Public health officials recommended avoiding public and crowded or closed-in settings and places (Cucinotta & Vanelli, 2020), whereas reasonable accommodation measures are posed as essential in reducing contacts and the risk of contamination (United Nations Human Rights, 2020). Regarding the health of people with disabilities in global terms, three public health areas were prioritized (Boyle et al., 2020). First, new surveillance or data collection systems are needed to assure that the right types of health protection actions (prevention, treatment, and mitigation) are arranged, including the right types of data. Secondly, research is needed on strategies of improving the health protection measures for people living with disabilities during the outbreak. Last, the question of equity in access to medical care for people with disabilities due to the need to ration life-saving medical equipment is open (Boyle et al., 2020).

The impact that COVID-19 on service delivery for people living with disabilities

Physical, or social, distancing has a profound impact on the delivery of disability services. Globally, schools, day-care and rehabilitation centres have been completely closed or suspended or have reduced their activity in terms of personnel or working hours, leaving individuals with disabilities and their families to come up against a situation. Solving problematic situations of this type requires quick, skilful and proficient adaptation of standard practices. Service disruptions were widespread, with increasing levels of disruption to services as a country was moving from sporadic cases to community transmission of the coronavirus (WHO, 2020a). In almost two-thirds (63%) of countries, disruptions of rehabilitation services was noted, whereas only 42% of low-income countries had included services for non-communicable diseases in their national COVID-19 preparedness and response plans (WHO, 2020a). Furthermore, the importance of implementation of the biopsychosocial model is fully expressed in the context of the COVID-19 pandemic, as opposed to the medical model. Therefore, research is needed on inventive approaches that involve individuals with disabilities, their family members or caregivers.

New research should also contribute to understanding the impact that COVID-19 has on service delivery as a step toward evidence-based service decisions. One possible suggestion would refer to the experiences of providers of service support to people with disabilities in outpatient or inpatient rehabilitation, providers of family-centred care, service providers working in clinics, as well as special educators. Research questions would relate to the problems of adaptation and management of clinical work and service delivery caused by COVID-19, the challenges, and future directions. It is necessary to supplement those findings qualitatively and clarify the reasons for poor access or no access to service delivery for people vulnerable to COVID-19, including people with disabilities. One of the earliest international studies on the topic has assessed COVID-19-related changes and adaptations in practices among health care professionals working with people with spinal cord injury and disease (Stillman et al., 2020). Although only the perspective of health care professionals was directly explored, attention was drawn to several topics needing immediate attention. First, pandemic-specific information needs and patient concerns, mostly about their vulnerability to COVID-19, need to be addressed. Second,

standardization of the best-practice protocols in the rehabilitation should be initiated and implemented. Here, the urgency of modifying the outpatient and inpatient practices to reduce the exposure of individuals from this population was emphasized, as well.

As an illustration, service gaps might be identified by using geographic information system methods or a spatial analysis (Lakhani, 2020). That way, the geographic dispersion of areas with significantly high numbers or percentages of people with disabilities, and also poor access or no access to certain services could be identified. The results thus obtained should have a key role in the planning of services and resource providing, improving psychosocial support and development of a mobile specialist consultant team (Lakhani, 2020).

Related to socio-economic aspects of COVID-19, a possible explanation of why certain groups are considered to be increasingly vulnerable can be found in the literature. Saadat et al. (2020) have identified three main criteria: population density, household size and physical, or social, distancing level, in addition to several other socio-economic factors such as urban and rural settings, education level, financial difficulties and lifestyle. These socio-economic factors should inevitably be considered in disability studies related to COVID-19. As mentioned, people with disabilities may have an increased risk of COVID-19. However, this can be explained not only by their disproportional representation among older populations and various underlying health conditions but by their disproportional representation among those living in poverty, as well (UNICEF, 2020).

As explained in the case of Romania, the risk of people with disabilities living in residential care facilities of being exposed to a COVID-19 infection can be explored by the social and economic geography of these institutions (Safta-Zecheria, 2020). Residential institutions are usually stationed in peripheral regions with many economic difficulties and fewer employment opportunities for locals, which is common in East European countries. At the beginning of the pandemic, a large number of labour migrants returned to that same regions. They were considered an additional risk of spreading the COVID-19 infection to residential care institutions since many of them are family members or members of the same communities as employees in residential institutions. Future research should take into account the geographic specificity of each area or region by conducting spatial analysis.

New research opportunities for telemedicine and telehealth

Certainly, the topic to which new research within disability studies will be dedicated is the telemedicine or telehealth, that is, telemedicine system, technology, clinical applications, benefits and effectiveness, implementation and integration within health systems, and patient satisfaction (Fazzi & Galli, 2020; Haines & Berney, 2020; Hart et al., 2020; Longo et al., 2020; Mesa Vieira et al., 2020; O'Connell et al., 2020). Telehealth refers to “the use of telecommunications and virtual technology to deliver health care outside of traditional health-care facilities”, as outlined by the WHO (2020b). Contact with relevant telehealth services is listed among actions and protective measures that can be taken by people with disabilities or their family members to ensure the continuation of the care and support, mainly for questions or non-urgent medical assistance. At the same time, telehealth arrangement is listed among actions that can be taken by health-care workers to fulfil general health needs of people with disabilities, their rehabilitation needs and, where appropriate, COVID-19 related needs. Disability service providers may use the telehealth system and communication platforms to communicate frequently with people living with disability and their support networks.

Recently, the use of telemedicine is confirmed as socioeconomically and environmentally directly supportive of both patient and caregivers (Irgens et al., 2018). Still, optimal methods for utilization, methodology and efficacy remained insufficiently empirically grounded. Starting from the need that further development and expansion of telehealth services need to be beneficial for people living with disabilities and their caregivers (Irgens et al., 2018), a few research problem areas related to COVID-19 can be recognized. Specifically, there is an urgent need to explore, set and recommend standards of care and best-practice protocols. Current academic research opportunities include accessibility of technology, treatment interventions and their efficacy, followed by user-participation, safety, effectiveness, and cost-benefit (Irgens et al., 2018). Another important issue concerns the utility of telemedicine or telehealth services to monitor, adjust and improve home therapy plans. Finally, the possible mediating role of the telemedicine in the effect of current COVID-19 crisis on the quality of life in the population of people living with disabilities and their families should be considered, as well.

To preserve the continuity of physical, occupational, speech or other rehabilitation programs, interventions and therapies, the role of families, as the immediate environment, and the implementation of family-centred practices become a priority (Longo et al., 2020). Family-centred care has become particularly important under these recent, changed and challenging circumstances (Hart et al., 2020). Research should focus on issues of practical implementation. Is access to new technologies achievable and reasonable from a financial point of view and what are the mechanisms for overcoming difficulties and financing the necessary information and communication technology? What are the most effective and efficient training models and approaches in their use? What alternative communication channels are available and adequate as a replacement, in the given circumstances?

The role of telemedicine and telehealth platforms in home-based programs for people living with disabilities

When it comes to home-based disability services and telehealth platforms, they are recommended as ways to reduce potential exposure to COVID-19 during provision of disability services (WHO, 2020b). Since practitioners and experts are invited to switch to a telehealth delivery model, governments and policymakers are called to ensure the continuation of work and education and the provision of rehabilitation services through information and communication technologies (Economic Commission for Latin America and the Caribbean, 2020; Haines & Berney, 2020).

Numerous researches of the implementation of home-based programs and their benefits can be found in the literature, as well as a model of the proposed phases of their implementation in practice (Novak & Cusick, 2006). For example, a five-phase model of home programme approach suggests the collaboration between therapist and parent or caregiver of the child (1) and mutually agreed goals focused on family (2). Next are the selection and construction of home programme therapeutic activities, which should be collaborative and embedded within everyday tasks (3). The implementation of the programme at home needs to be supported, with regular contacts and face to face follow-ups to ensure that the programme is practically feasible and following the family's needs (4). Subsequently, the fifth suggested phase is the evaluation of the outcomes, which should be ongoing and set from a family point of view (5).

Following the above, contemporary research and work on the implementation of family-centred care should be initiated or intensified. Given the limited empirical evidence of efficiency and effectiveness, there is insufficient information about program components that might influence family participation (Novak & Cusick, 2006). Specific priority fields in disability studies might refer to the creation and development of clinical guidelines for home-based programs, followed by the evaluation of their impact and available resources. Bearing in mind the specifics of each environment, it could be considered urgent to examine barriers to the development and implementation of this type of program at the national level, from the aspect of all actors and stakeholders involved in the process. Previous studies support this claim. The possible underrepresentation of the concept of participation and family-centred work principles in service planning and evaluation of the applied program's outcomes was recently explored in Serbia, from the perspective of parents of children with cerebral palsy (Milićević & Nedović, in press). Also, the attention was called to the dominant orientation of services and professional support in Serbia to individual, functional achievements and consequent lack of effect in the social context, as reported earlier (Milićević & Nedović, 2017).

Another research topic that can be found in the new literature is the need for educational tools and communication strategies, designed and planned not only for people living with disabilities but also for their families and caregivers (Human Rights Watch, 2020; Stillman et al., 2020). Moreover, certain and no less important technical preconditions must be explored. The implementation of family-centred care and home-based programs, including school and educational ones, depends on technology. In other words, the use of technology-dependent services implies accessible and stable internet access, possession of a personal or family computer and/or smartphone, but also technological literacy. However, there are differences in the fulfilment of the stated technical preconditions, mainly caused by socio-demographic disparities, such as age, income, place of residence, education. Accordingly, one research area should be focused on the identification of barriers to establishing a primary contact and communication with families. The other one should be directed to strategies to reduce or minimize the barriers and facilitate family involvement.

The raising ethical issues – human rights and the rights of persons with disabilities

Another line of research is dedicated to raising ethical issues and considerations as the present pandemic was spreading. As explained by Pauls et al. (2020), there are strong ethical justifications for robust triage systems when capacity and resources to provide critical care to all patients are overwhelmed. There were also warnings on difficult moral dilemmas and decisions on which COVID-19 affected patients should go on life-saving treatment as a result of the shortage of medical equipment (Merrick, 2020) and explanations that using disability as a factor in denying life-saving treatment was discrimination against individuals with disabilities because of their disabilities (Bagenstos, 2020). However, certain criteria should not be applied isolated within the decision-making process, including the presence of mental and/or physical disability. Additionally, serious concerns were also noted regarding disability and human rights (Human Rights Watch, 2020). There are some reports that vulnerable populations, including people living with disabilities, “have often been talked about as if they were ‘disposable’ or ‘expendable’” (Grzelka, 2020, p. 122). It is important to acknowledge the distress that many people with disabilities feel due to ableist and ageist attitudes and fear of becoming neglected, abandoned or forgotten. For example, the public in Poland was alerted by employees of a nursing home for people with intellectual disabilities because they were not properly equipped with masks and other personal protective equipment (Klauziński, 2020, as cited in Grzelka, 2020).

On the other hand, considering those decisions of the Spanish government in crisis management that can be characterized as wrong ones, serious accusations were made against the government’s decision to allow people with intellectual disabilities or autism to go out into the streets, regardless of their best intentions (Arango, 2020). This position was strengthened by recalling that people from this population should not become infected because they were not eligible for intensive care, in addition to very difficult managing and the increased risk of infection of relatives who were accompanying them. In Serbia, a range of issues and problems were opened. Among them were how to ensure the accessibility and availability of information and how to solve the problem of leaving the house, how could support services operate, how could personal assistants come to the homes of service users or people with disabilities to help them meet basic needs (Rogač, 2020). During the first several weeks of the state of emergency with

the police lockdown in Serbia, parents of children with autism spectrum disorders have experienced a lack of support and feelings of helplessness (Stankovic et al., 2020). Many of the parents have handled their children on their own, which suggests that the government needs better plans and strategies for future similar situations.

One of the topics that have been given special priority is related to the specialized and legitimate concerns that health care may be denied to them in cases when lawmakers or policymakers and health care systems determine who will receive limited services, including treatment rationing situations (O’Connell et al., 2020). More precisely, this possibility can be related to people living with disabilities in general.

Accordingly, it is necessary to retrospectively determine the relationship and responsibility of individual actors in control for achieving and maintaining human rights and ensuring guaranteed human rights and the rights of persons with disabilities. If they live at home and rely on community-based social care services, have their basic daily needs been met? If they live in community, have they been provided with social support and services? If they live in institutions or closed settings, have their health been protected and have their needs for family and connection been addressed? Have their specific needs been recognised when prevention strategies were considered, locally and nationally? The answers to these questions are deciding for rights-based strategies and inclusive responses in future outbreaks and health emergencies (Schariti, 2020). For now, three key barriers to inclusive preparedness and response planning are described. The first barrier relates to inequities in access to public health messaging. The other two barriers relate to discontinuity in service provision and possible additional barriers to health care (Armitage & Nellums, 2020).

High-quality research standards – the importance of scientific and valid COVID-19 related data

Furthermore, high-quality research on the overall or specific effects of the COVID-19 pandemic across the population of people living with disabilities, with a national or global perspective, can only be based on high-quality research data. An appropriate registry or database is required to gather the necessary and valid information. Population-based registries have an important role in determining the prevalence, aetiology, distribution,

frequency and severity of a particular disability in a national or international region (Hurley et al., 2011). Besides, much of our understanding of a particular disability has come from international population-based registers or the cooperation of several national registers (Hurley et al., 2011). Having a national registry is a central prerequisite to systematically analyse the current situation and the needs of people living with disabilities and their families (Arneson et al., 2009). As suggested earlier in the case of children with cerebral palsy (Milićević, 2019), the founding of a national registry in Serbia will allow planning and evaluating of services, interventions and programs within the scope of special education and rehabilitation work in a realistic framework (Demeši Drljan, 2011; Milićević, 2016). Comprehensive information is required to determine the basic, health and social needs of people living with disabilities and their families. Seen from the long-term perspective, the founding of a registry of this kind at the national level is imperative for our future actions. Overall, a multidisciplinary research response is needed, coordinated at the national level, consulting with people with lived experience, to develop national evidence-based strategies and protocols, but also to avoid data waste and participant fatigue and consequent refusal to participate in research (Holmes et al., 2020).

Conclusion

The novel coronavirus disease (COVID-19) pandemic crisis presents a more considerable challenge to the population of people living with disabilities. Without doubt, COVID-19 has caused concerns suddenly, posing numerous challenges in front of the scientific and professional international community. It is recognised that the present pandemic has the capacity to intensify existing inequalities, particularly affecting vulnerable populations, including people living with disabilities. The mechanisms of effect and reversibility of consequences have yet to be examined and determined. In light of the present COVID-19 pandemic, the vulnerabilities of people with disabilities, elderly people, and people with chronic conditions are being highlighted. Direct access of many people living with disabilities and their families to needed physical, occupational, speech or other rehabilitation programs, interventions and therapies has been interrupted.

Health-related topics include mental health, viral diseases, diagnoses and treatments, maternal care and paediatrics, and genetics, as well as

cognitive sequelae and various neurological manifestations in COVID-19 survivors with disabilities. Prioritized topics in public health refer to new surveillance or data collection systems, strategies of improving the health protection measures for people living with disabilities, and the question of equity in access to medical care.

The impact that COVID-19 have on service delivery for people living with disabilities directs future research towards the importance of implementation of the biopsychosocial model and evidence-based service decisions. In addition to problems of adaptation and management of outpatient and inpatient clinical work, immediate attention should be focused on pandemic-specific information needs and concerns, standardization of the best-practice rehabilitation protocols. Vulnerabilities of people with disabilities need to be explored by including certain socio-economic factors. Geographic information system methods or a spatial analysis is recommended.

Particular attention was called to the research and innovative approaches to telehealth in therapeutic, rehabilitation, assessment and follow-up purposes, as well as the raising ethical issues related to using disability as a factor in denying life-saving treatment. High-quality research standards, multidisciplinary and intersectoral approach with a global perspective and international comparisons are suggested.

The gap between the implementation of knowledge and implementation of action can be bridge by the evidence-based methodology. The upcoming findings of disability studies would certainly improve the society's ability to adjust and prepare for a re-emergence of COVID-19.

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ISTRAŽIVAČKI PRIORITETI U STUDIJAMA OMETENOSTI VEZANI ZA COVID-19

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Sažetak

Kriza izazvana pandemijom novog korona virusa (COVID-19) predstavlja veliki izazov za populaciju osoba koje žive sa invaliditetom. Glavni cilj ovog rada je bio da se identifikuju novonastala istraživačka područja u studijama ometenosti koja se odnose na COVID-19 kako bi se odredili neposredni prioriteti i dugoročne strategije za naučno istraživanje i praksu zasnovanu na dokazima. Razmotrene su prioritetne teme u javnom zdravstvu i opšte zdravstvene teme, uključujući kognitivne posledice i različite neurološke manifestacije kod osoba sa ometenošću koje su se oporavile od oboljenja COVID-19, nove sisteme nadzora ili prikupljanja podataka, strategije poboljšanja mera zdravstvene zaštite za osobe sa ometenošću, kao i pitanje jednakosti u pristupu medicinskoj nezi. Prekidi u pruženju servisnih usluga ukazali su na važnost primene biopsihosocijalnog modela i odluka o uslugama zasnovanih na dokazima, ali i da bi buduća istraživanja trebala da budu usmerena na probleme adaptiranja i upravljanja ambulantnim i bolničkim kliničkim radom, na probleme vezane za potrebe za specifičnim informacijama o pandemiji i na standardizaciju najboljih protokola vezanih za rehabilitaciju. Preporučene su metode geografskog informacionog sistema ili prostorne analize. Posebna pažnja je posvećena istraživanjima i inovativnim pristupima telezdravlju ili telemedicini primenjenoj u terapijske i rehabilitacione svrhe, u svrhe procene i praćenja, kao i sve važnijim etičkim pitanjima koja se odnose na navođenje invaliditeta kao faktora opravdavanja uskraćivanja lečenja koje bi moglo da osobi spasi život. Predloženi su visokokvalitetni istraživački standardi, multidisciplinarni i međusektorski pristup sa globalnom perspektivom i međunarodnim upoređivanjima rezultata istraživanja. Predstojeći nalazi studija ometenosti bi sigurno mogli da poboljšaju spremnost društva da se prilagodi i pripremi za ponovno pojavljivanje COVID-19.

Ključne reči: COVID-19, koronavirus, ometenost, osobe sa invaliditetom, istraživanje, Srbija