

REVIEWS

THE IMPACT OF COVID-19 STATE MEASURES ON CHILDREN WITH DEVELOPMENTAL DISABILITIES: SERVICE AND RESEARCH PRIORITIES FROM THREE EUROPEAN COUNTRIES

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ABSTRACT

INTRODUCTION: The effect of social distancing and closure of treatment facilities due to the COVID-19 pandemic has been disruptive for children with disabilities and their families.

AIM: The current study aims to enable research data by synthesizing the impact of COVID-19 measures on children with developmental disabilities applied in Bulgaria, Sweden, and Germany.

MATERIALS AND METHODS: A systematic literature search was conducted following PRISMA protocols. Databases searched included Google Scholar and PubMed for papers published December 2019–November 2020 using four keyword categories. We reviewed 1691 abstracts, 35 of which met our inclusion criteria for a full review. After reviewing the full texts of the articles and applying the study exclusion criteria, four articles were included in the current analysis.

RESULTS: Two studies reported results from Bulgaria; while the other two discussed the impact comparing Sweden and Germany to other Western European countries. All studies discussed the highly inadequate governmental decisions and policy-making during the initial wave in all three countries. No government took any decision specifically aiming at mitigating the risk and its impact on children with disabilities and their families.

CONCLUSION: Although some good practice examples have emerged across Europe, additional efforts will be needed to ensure that health crisis responses are disability-inclusive. Mindful leadership at policy and program levels could guarantee the success of such efforts in the future.

Keywords: COVID-19, state measures, children, disabilities, child policies, European countries

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INTRODUCTION

The coronavirus disease 2019 (COVID-19) has been present for more than a year now. Still, it continues to affect people's health, leaving a huge imprint on various aspects of their life (1). However, the effect of the pandemic has not been equal across populations. Marginalized and socially disadvantaged groups were among the most affected by the disease

(2). That said, there is a rising number of publications on the COVID-19 pandemic and its influence on children with disabilities (3–6). Studies report on how the pandemic has disrupted essential service delivery routine treatment for children with disabilities and led to decreased access or absolute loss of therapy services (7,8). Additionally, studies discuss the negative effect of the pandemic on children's physical and mental health, social life, and education (9,10).

Since the beginning of the pandemic, governments around the world have tested different strategies to battle the disease and its effects on the general population. The fact that the disease was novel and nobody imagined that it could become a world-spread problem has brought late and inadequate reactions to it and examples of countries like Italy, the USA, and Brazil speak for themselves. Yet, in public health crises such as the inadequate responses to the coronavirus outbreak have led to more exclusion and worsening of the condition of living of socially disadvantaged groups such as children with disabilities and their families (6). According to the 2020 Disability Rights Monitoring (DRM) report, countries overlooked the need for specific action with vulnerable populations, i.e., people with disabilities, which postponed the discussion on the possible implementation of disability-inclusive response to COVID-19 (11,12). Policymakers, both at national and global levels, have relapsed to treating persons with disabilities as objects of care or control, undermining many of the gains of recent years to enhance citizenship, rights, and inclusion (11). The consequences of such inactions were dramatic for people with disabilities and their families; the report points out that in countries such as the USA and the UK, for example, more than half of the victims of the coronavirus outbreak during the first waves were people with disabilities. Moreover, the DRM report highlights four problematic areas that were unattended by government officials around the world: 1) the inadequate measure to protect persons with disabilities in institutions; 2) significant and fatal breakdown of community support; 3) disproportionate impact on persons with disabilities; 4) denial of access to healthcare (11).

Regarding children with disabilities, governments have taken little or no action to protect their lives, health, and safety, with concerns including

the lack of provision of personal protective equipment, the withdrawal of the limited support provided to families, and the near-total exclusion of children with disabilities from education as schools were closed or adopted online teaching environments which were largely inaccessible (11). Such an absence of child-specific measures during the pandemic has placed children with disabilities in compounded vulnerability. Moreover, there is scarce literature data on the effectiveness of service delivery and treatment during the pandemic, which has questioned the quality of care and the progress made by children prior to COVID-19 (3). According to Neece and colleagues (2020), such lack of knowledge on the working models in different cultural and socioeconomic settings could be an obstacle for better services during the transition to post-pandemic life (13).

Coronavirus Country Response Types. European Experience and Child Protection Policies

The initial response of governments around the world to the emergence of the SARS-CoV-2 virus included two distinct approaches: the herd-immunity approach and the enforcement of partial or full lockdown of countries.

Despite being an ideal concept, the idea of herd immunity was passionately debated at the beginning of the coronavirus pandemic. Scientists argued that reaching a threshold of 80% of people immune to the virus was a plausible (if there is an effective vaccine) and natural way (when people get sick) for population immunity (14). However, achieving herd immunity required an intentional sacrifice of people, in terms of loss of life and long-term consequences of suffering (14). In Sweden, where herd immunity was initially aimed, deaths rates reached 1330 per million people, and that forced the Swedish Corona Commission to admit that “the single most important factor behind the major outbreaks and the high number of deaths in [elderly] residential care is the overall spread of the virus in the society” (15). Not surprisingly, scientists reconsidered the idea of achieving herd immunity to be “not only highly unethical, but also unachievable” (16).

The second approach that governments undertook to fight the spread of the SARS-CoV-2 virus was the enforcement of partial or full lockdowns. This is still an ongoing measure as the vaccination rates

European countries in lockdown

Dates and severity of restricted internal movement by country

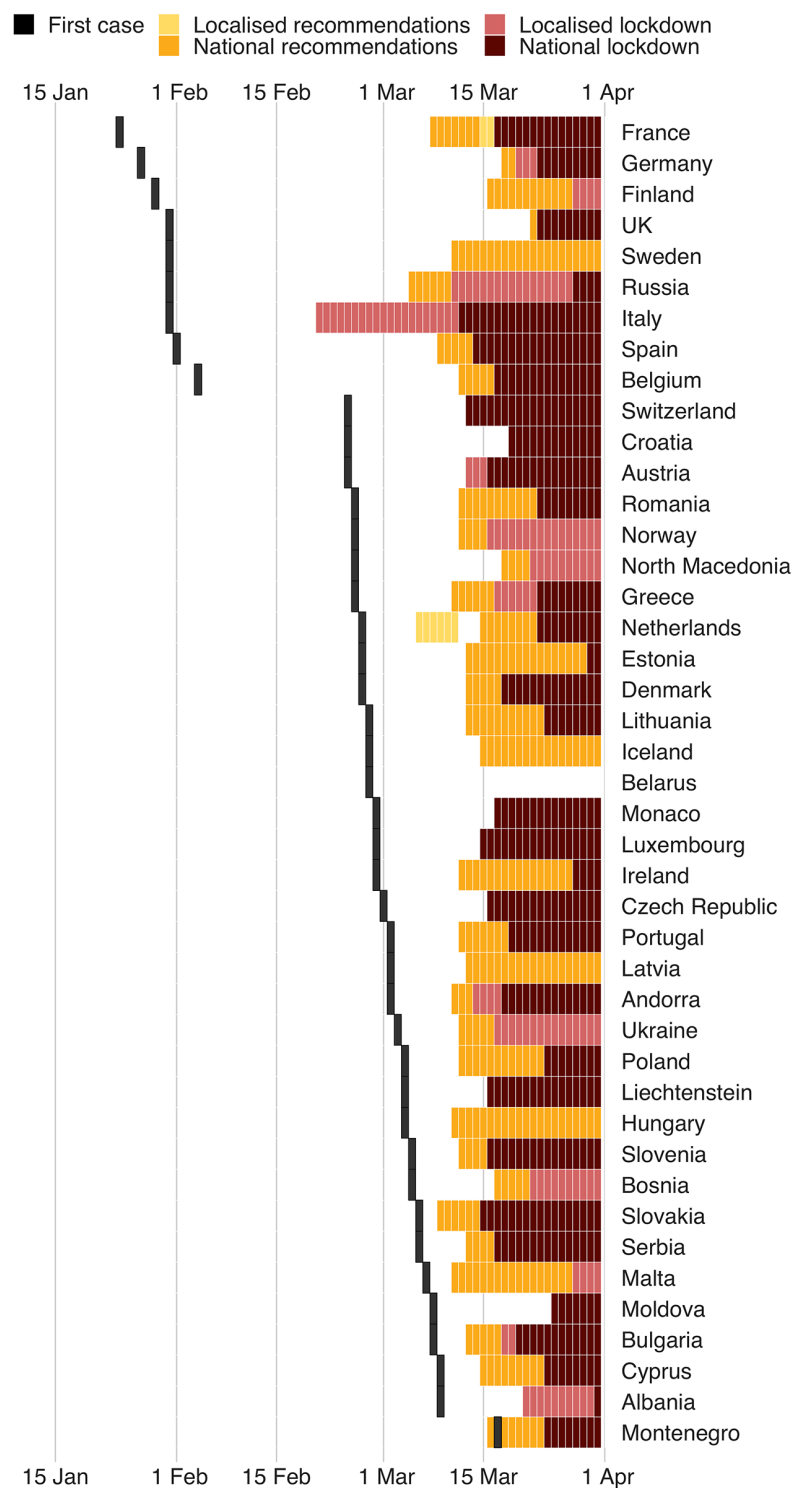


Fig. 1. European countries in lockdown during the first wave of coronavirus spread on the continent (source: Oxford COVID-19 Government Response Tracker, BBC Research [<https://www.bbc.com/news/world-52103747>])

throughout Europe and the rest of the world are not satisfactory enough to ensure the safety of the unvaccinated population groups (see <https://ourworldindata.org/covid-vaccinations>). Lockdowns, wearing masks, and keeping social distancing turned out to be working measures that can buy time until better options are offered (vaccines or treatment). Notwithstanding their great socioeconomic costs, studies have documented their effectiveness in slowing down the transmission of the disease (17, 18). Most countries in Europe have applied this approach according to the Oxford COVID-19 Government Response Tracker [BBC Research] (see Fig. 1).

The lockdown approach undertaken by most European countries had adverse consequences for children with disabilities. Evidence shows that they were least likely to benefit from distance learning, remote treatment services, and social isolation as many countries did not have working tailored policies that could battle the impact of the pandemic on children's lives but at the same time to address far-reaching problems, such as lack of social support, access to the internet, accessible learning and treatment materials (12). Local measures and interventions were among the scarce efforts ensuring children's equity and inclusion in the COVID-19 response of each European country. In 2021, a year after the beginning of the pandemic, the European Union and UNICEF announced the start of a program trying to mitigate the consequences of the pandemic and safeguarding children's rights to education and protection ensuring national systems delivering services to the most vulnerable children in an equitable and inclusive manner (19). This is the first united initiative that will address the specific needs of children in Europe. However, we need to point out that this program comes as a post-fact response to the problems of this population. Unfortunately, due to the nature of the disease, many countries did not feel prepared to timely and adequately respond to the virus. Needless to say, that fact resulted in a lack of specific reactions and policies aiming to mitigate the severity of the problem among the most vulnerable populations (20).

Considering the lack of official policies addressing the COVID-19 effects on the life and health of children with disabilities living in European coun-

tries and the gaps in the existing literature on the effectiveness of the treatment and service delivery to children with disabilities during the COVID-19 measures, the current study aimed to enable research data on the experiences of COVID-19 response policies and treatment interventions applied to children with developmental disabilities in three European countries—Bulgaria, Germany, and Sweden. The rationale of the country's choice is based on the fact that they represent countries that have adopted different response measures and are states with different levels of socioeconomic development. Additionally, the focus on children with developmental disabilities is based on the premise that they represent the fastest growing and unattended group of children with disabilities among others (21).

METHODS

Search Strategies

A systematic literature search was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocols. Electronic databases searched included Google Scholar and PubMed from scientific papers or grey literature that were published from December 2019 to November 2020. The following keywords were used in English and Bulgarian: child, disabilities, COVID, SARS, neurological impairment, services, treatment, therapy, provider, developmental delays, autism, ADHD, hyperactivity, learning disabilities, Asperger's syndrome, Rett syndrome. Each of these keywords was chosen because of their relevance to the purpose of this study and our inclusion criteria. They were variously combined to retrieve the most appropriate articles. Only in Google Scholar were successfully identified sources for this literature review. No results were found in PubMed. Thus, Google Scholar has been used as the main scientific database for our search. We additionally manually searched both in Bulgarian and German for additional references to make sure that our research was comprehensive.

Inclusion Criteria

We reviewed 1691 abstracts, 35 of which met our inclusion criteria for a full review, resulting in 4 articles that are part of the current analysis. (Fig. 2) The inclusion criteria consisted of:

1. reports of COVID-19 measures;

2. children with disabilities, including a wide age range such as infants and adolescents (up to 25 years);
3. service delivery and treatment;
4. Bulgaria, Germany, and Sweden.

Data Extraction

All four authors screened the abstracts and titles of all 35 articles and shared subjective selections for further review through an Excel sheet. Each author was then responsible to crosscheck and review the selection by another author for cross accountability. Finally, through a group video conference, we discussed discrepancies and justifications for the se-

lections. A detailed description of the selection process is reported in Fig. 2.

RESULTS

All studies were published in 2020 during the first year of the coronavirus pandemic in Europe. Two studies reported results from Bulgaria and were published in Bulgarian (22,23) and the other two discussed the impact of COVID-19 on children with disabilities comparing Sweden and Germany to other Western European countries (9,24). The design of the studies varied. Three studies were literature reviews (9,23); the rest of the studies included primary strategies of collecting data via interviews and sur-

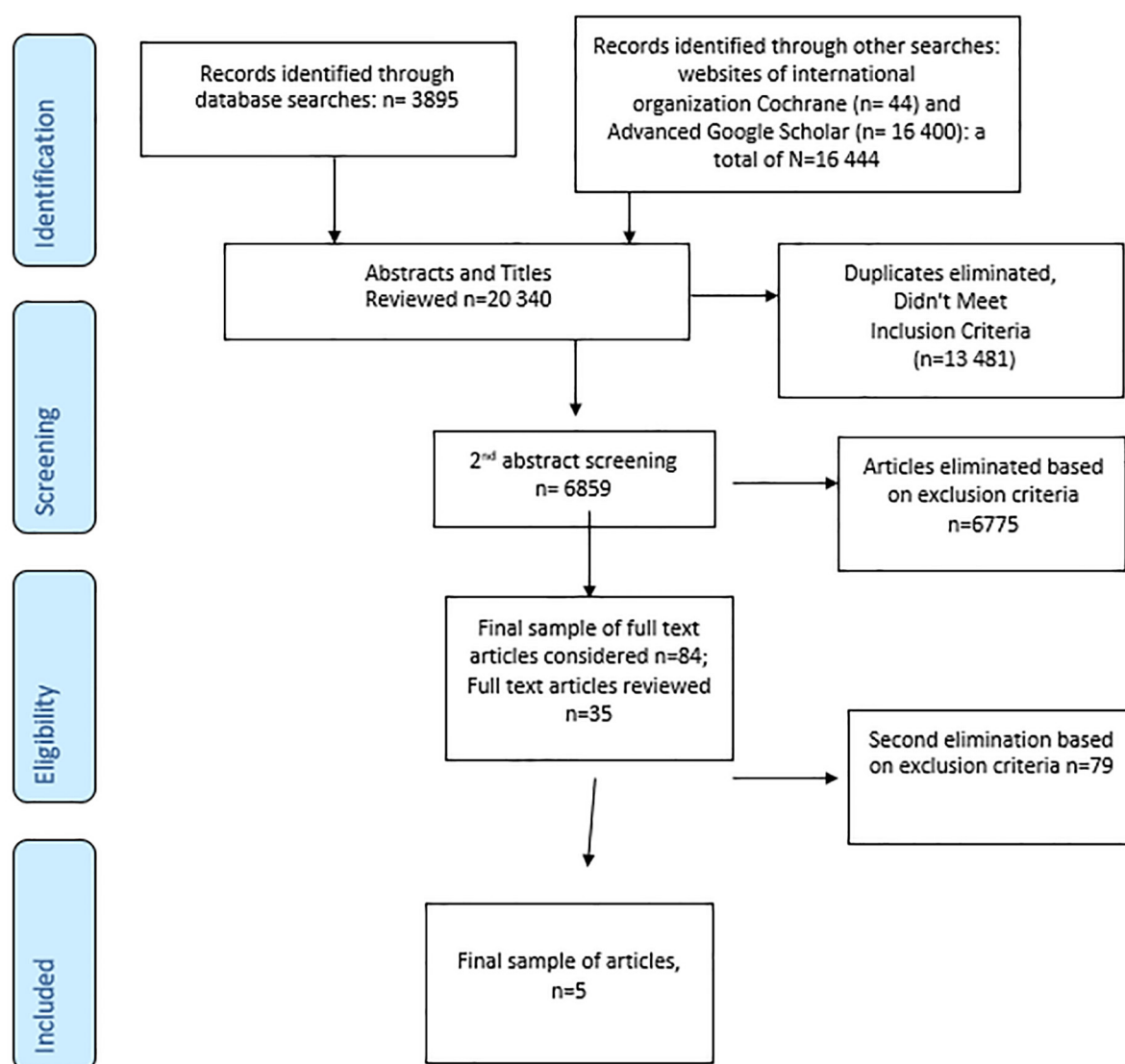


Fig. 2. PRISMA flow chart of the search strategy of the present systematic review

Table 1. Results

First Author	Title	Date of Publication	Country	Study Design and Data Collection Tool	Study Population	Specifics Related to Children with Disabilities	Treatment and Service Provision	Governmental Approaches to the COVID Crisis	Reported Outcomes
Albayrak	Clinical Experience on Video Consultation in Preterm Follow-Up Care in Times of the COVID-19 Pandemic	2020	Germany	Narrative/comment	30 families of preterm infants; gestational age below 34 weeks	Corrected age of 3, 6 and 9 months and preschool age, who do not have disabilities, but a probability of such	Neurological and interdisciplinary follow-up video consultations	Telemedicine was used in the follow-up care of premature babies in Germany, but that strategy was not widely adopted	Parents were empowered by self-examining their children and being able to learn more about their neurodevelopment; children were calm and comfortable because of being in a family environment
Petrova	Social Services in the Community in a State of Emergency (Социалните услуги в общността в условията на извънредно положение)	2020	Bulgaria	Cross-sectional; online questionnaire and in-depth interviews with head managers of social services for children and families at risk were performed	113 social services throughout Bulgaria; 5 in-depth interviews	Major problem encountered by professionals working with children with disabilities is having to deal with online learning	Service providers share difficulty in deepening relationships with new clients when working online and difficult interinstitutional partnership	No national response but an organizational one was performed. More frequent service provision; NGO specialists share greater satisfaction by their clients due to greater support from the institution, but also to the more frequent search	Younger children are easily distracted by devices; in this case parents must intervene, in turn they feel satisfied that they have been included
Tomova	Impact of Social Isolation on Everyday Life of Visually Impaired People (Отражение на социалната изолация върху ежедневието на зрително затруднените лица)	2020	Bulgaria	Cross-sectional; literature review, and online questionnaire	26 individuals with visual impairments	There are respondents who are aged 15–20	Despite the changed way of life, the daily activities of the visually impaired did not undergo special changes and the daily life was similar in the way before the imposed measures	No governmental response was formed. In order to help people with visual impairments, international organizations and national organizations began to publish instructions and support materials in order to facilitate their daily lives	High level of awareness among the visually impaired about the imposed restrictions for physical distancing; those with sufficient technical skills and access to telephones and/or computers had adequate access to information

Fegert	Challenges and Burden of the Coronavirus 2019 (COVID-19) Pandemic for Child and Adolescent Mental Health: a Narrative Review to Highlight Clinical and Research Needs in the Acute Phase and the Long Return to Normality	2020	All over Europe	Selective literature review	Experiences with CAP treatment and personal communication with professionals (CAP) in child and adolescent psychiatry	Children and adolescents having CAP training	- interruption of child protection services and currently existing support and supervision programs by youth welfare agencies - limited leisure time activities - increased demand for mental health professionals - decreased support, cancelled treatments, which led to delay of diagnosis/treatment Additionally: maladaptive coping of parents increases	No governmental support but recommendations were provided: - ensure the support of the child treatment - ensure technical requirements for telepsychiatry	- strengthened family bonds - increased social support; - abuse - increased anxiety - stress
Thorell	Psychosocial Effects of Homeschooling During the COVID-19 Pandemic: Differences between Seven European Countries and Between Children with and Without Mental Health Conditions	2020	Across Europe (UK, Sweden, Spain, Belgium, Netherlands, Germany, Italy)	Cross-sectional; online survey	6720 parents (2002) with a child with mental health condition and 4718 without)	Some children with mental health conditions (esp. ADHD and autism)	- mental health problems (e.g., canceled treatments, delays in optimization of meds) - negative effects on homeschooling and increased burden on families	- in Germany: many children had no teacher contact at all - in Sweden: homeschooling for children above 15 was provided - unaddressed social disparities among families with disabilities	Difficulties homeschooling in younger children—increased conflicts with children and between adults - widened social disparities - increased depression rates

veys (22,24). Samples included staff working in social service institutions (9,22), parents of children with disabilities (24) and individuals with disabilities aged 15–20 years (23). Additionally, sample populations included children with disabilities along with their caregivers (9,23,24).

Studies were very heterogeneous in nature, which made the generalization difficult.

Half of the studies highlighted the importance of the necessity of the parents to intervene (22, 25), who in turn felt satisfied that they were included in the child's care and could successfully help their children (22). A highlighted benefit was that children were much calmer in the familiar home environment than in the care centers (24). Additionally, Bulgarian findings shared that service providers found it difficult to work remotely with younger children as they got easily distracted by the technical devices (23). Parents have successfully taken on the role of facilitators and aided the work, but this could not replace specialized support that requires demonstration and physical contact. Thus, it did not achieve the same effect as in direct work (22). Furthermore, findings from fieldwork with visually impaired youth showed that their daily activities did not undergo special changes despite the altered way of life. A corresponding survey has been conducted, which includes children and adolescents who were in the age range of 15–20 years, and showed a high level of awareness about the imposed restrictions for physical distancing. Those with sufficient technical skills and access to telephones and/or computers had adequate access to information on how to follow the measures and how to provide the satisfactory additional necessary protection (23).

All studies shared the highly inadequate governmental decisions and policy-making during the initial wave of the health crisis caused by the COVID-19 pandemic in all three countries. No government took any decision specifically aiming at mitigating the risk of SARS-CoV-2 and its impact on children with disabilities and their families. Separate initiatives undertaken by local and national NGOs were reported as working. For example, supervision and distant training (22), support materials and guidelines were used for youth with visual impairments (9,23), adapted online teaching, but not effectively,

among children with disabilities and their families as additional support was reported as needed (i.e., economic, social, technical support) (24).

Studies reported various positive effects on children with disabilities during the pandemic. Children felt more comfortable and calmer, except for young children who were more likely to be distracted (22). Children with disabilities improved their technical skills such as working on a computer and technical devices (23); and strengthened family bonds (9). Additionally, parents were actively involved in the children's educational and treatment activities, which was discussed both positively for the parent-child relationship and negatively because of the burden and the stress on parents and caregivers (9,24).

DISCUSSION

The present review aimed at comparing the experiences of children with developmental disabilities during the first year of the coronavirus pandemic in three European countries. More specifically, the paper tried to reveal if there were any differences in the service delivery and policy-making in times of health emergencies, such as COVID-19, in countries with different socioeconomic levels and different approaches to responding to the pandemic. For the review, we selected Sweden—a country undertaking the herd-immunity response, Germany—a high-income country adopting lockdown measures, and Bulgaria—the poorest European country, adopting lockdown measures to fight the spread of the pandemic.

Undoubtedly, COVID-19 has impacted the lives of all people, including children with disabilities and their family members. Results from our review revealed that the pandemic had a negative effect on both children with disabilities and their families. Among the biggest barriers listed were the difficulty providing care and services remotely, lack of concentration, ineffective treatment, inaccessible schooling, increased stress among caregivers and parents, lack of standards and guidelines of work with children with disabilities in an online environment. Likewise, a UK study conducted among 241 parents of children with special educational needs and disabilities described that both children and parents experienced loss, worry, and changes in mood and behavior as a result of the rapid social changes that have

occurred (25). The economic downturn of the crisis on families with disabilities was also reported by different authors (10,26), deepening as a consequence the hurdles in health treatment and educational development of children during the pandemic. Failed technology, lack of technical skills in children, parents, and caregivers, no access to the internet, lack of appropriate learning materials were among the most direct factors impacting the educational and health service provision outcomes similarly discussed in the literature (27,28).

Despite that Bulgaria, Germany, and Sweden undertook two different approaches to respond to COVID-19, initial responses in all countries overlooked the prioritization of the needs of vulnerable populations such as children with developmental disabilities and their families. The effect of such political inaction impacted the progress of children in treatment programs as the advances made were reversed (28). Future actions aiming to deal with the post-COVID consequences will have to elaborate policies and practices that will allow children with disabilities and their families to receive the needed support that will help them to cope with the loss and gaps in their health and educational development during the COVID-19 period.

Yet, in the pandemic, there have been some positive aspects to consider. The ongoing crisis is a learning experience of what is needed and what should be done in the direct work with children with disabilities and their families (22). The pandemic also created the so-called equal start for all children in terms of working and studying in an online environment. Children with disabilities could participate on an equal basis as their non-disabled peers and thus avoid existing physical and communication barriers (29). Of course, equal participation typically requires financial and other resources. Therefore, for governments and societies in Europe to ensure the participation and protect children with disabilities from isolation and discrimination there must be draft policies and legal acts that guarantee their adequate safety protection and networks (30).

Some lessons can be drawn for future considerations from this review. First, the response to any health crisis should be disability-inclusive. This will increase the capacity of health, social, and economic

systems to adequately and appropriately respond to the needs of the most disadvantaged in the society. Second, states and providers should ensure the continuum of care after the pandemic is over. This will mitigate the negative consequences of the pandemic that marked children's development. Third, parents and caregivers have played an essential role as partners in the treatment and education of their children. Future standards and guidelines should consider training materials for parents as a way to help parents to better manage remotely the progress and development of their own child. Lastly, the pandemic aftermath has shown that research and evidence on the effectiveness of intervention on children with disabilities and their families during COVID are scarce. Future studies will need to study deeply and more rigorously the non-clinical effects of the pandemic on vulnerable populations and provide scientific examples of working models that could be used and be handy in a future health crisis.

CONCLUSION

Children with disabilities and their families are among the most vulnerable and directly affected by the impact of the coronavirus pandemic. Although some good practice examples have emerged across Europe, additional efforts will be needed to ensure that health crisis responses, such as the present one, are disability-inclusive from the planning stage. Strong and mindful leadership at policy and program levels can guarantee the success of such efforts in the future.

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