Effects of COVID-19 related restrictive measures on parents of children with developmental difficulties

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Abstract
Purpose – Social distancing and school closures have changed the lives of many parents around the globe. In addition to these problems, parents of children with developmental difficulties (DD) have faced additional stressors that make them even more susceptible to higher stress levels and the onset or worsening of anxiety or depression. Consequentially, these stressors may have an indirect effect on parental functioning and children with DD owing to the spillover effect.
Design/methodology/approach – The purpose of this paper is to draw attention to parents of children with DD through an overview of possible additional stressors that have appeared during the coronavirus pandemic in Croatia. In writing this viewpoint paper, three sources were consulted: official state documents, communication with professionals (e.g. speech therapists) and online support groups for parents of children with DD.
Findings – Restrictive measures during the lockdown led to a lack of both formal and informal support for parents of children with DD. Moreover, the possibility of infection led to higher levels of fear among these parents; children with DD also encountered problems coping with both the restrictive measures and the demands of distance learning.
Practical implications – This paper may present a good starting point for both governments and NGOs when discussing and planning further advancement in the quality of response to the COVID-19 pandemic and a “recovery” response after the crisis. This overview may provide better insight into COVID-19-related consequences among parents of children with DD, which is vital to increasing the effectiveness of future measures and actions.
Originality/value – Although some negative effects of the pandemic on children have already been discussed by several authors, little attention has been paid to parents, and even less so to parents of children with DD. This paper may even represent a pioneering work in exploring the consequences of the COVID-19 pandemic on this population group.
Keywords Distance learning, Social distance, COVID-19, Pandemic lockdown, Parents of children with difficulties, School closure
Paper type Viewpoint
childhood obesity (Rundle et al., 2020) or the exacerbation of existing inequalities (Van Lancker and Parolin, 2020). However, little attention has been paid to parents and guardians [1] of children with DD and the issues and obstacles they had to overcome during lockdown.

Even without the threat of pandemic, parents of children with DD face difficulties far beyond those faced by parents of typically developed children, including coping with the specific needs of children with DD and resulting difficulties in other life domains, such as financial strain, lack of free time or the need to embody roles other than simply that of the parent (Goudie et al., 2014; Resch et al., 2010; Seltzer et al., 2001). In caring for their children with DD, these parents rely on support, both formal and informal. In his process model of the determinants of parenting, Belsky (1984) considers social support one of the key components of competent parental functioning. Research shows social support can buffer the negative effects of stressors and help preserve well-being (WB), increase the sense of parental competence and provide much-needed leisure time (Armstrong et al., 2005). Informal support is a valuable emotional resource, but it can also be a highly tangible one. For example, parents of children with DD often spend most of their time with their children and thus have very little or no opportunity to leave them in somebody else’s care owing to their specific medical or other needs. To work, run errands, attend to the needs of other children or simply rest, they must often seek help from grandparents, relatives, or friends. Formal support also comes in a variety of forms, such as financial aid, medical treatment, or therapy for the child. In terms of education and schooling, formal support consists of curricular adjustments to accommodate to the abilities of children with DD; it also includes the use of assisted technology and teaching assistants, as well as the communication, competence and involvement of teachers or any other professional. Given the fact that parents are highly involved in the development of their children, it is important to consider how the restrictive measures implemented to fight COVID-19 changed their daily routines and what issues and obstacles arose as a result of it. This paper thus aims to provide an overview of possible additional stressors experienced by parents of children with DD in Croatia during the pandemic. In writing the paper, three sources were consulted: official state documents, communication with professionals (e.g. speech therapists) and online support groups for parents of children with DD.

During the lockdown, all but vital medical and therapeutic treatments were cancelled, leaving children with DD without the much-needed expert support that is crucial to their development. Research shows that parents of such children experience troubling thoughts about their child’s future (Heiman, 2002); this is likely the main reason why they strive to provide them with the support of professionals (e.g. occupational or speech therapists), whose main goal is to maintain or improve their functioning. The lack of such support can lead to stagnation in development or increases in developmental delay. For example, without support, children may lose some skills that experts had spent months developing. Although parents could attempt to compensate for the lack of professional support – and many of them likely endeavoured to do so by, e.g. practicing sorting with spoons and forks – many of these activities require expert knowledge or a special environment or both (e.g. sensory rooms). Under normal circumstances, professionals encourage parents to implement lessons their children learn during therapy in everyday life; these actions are usually reviewed by the therapist through interaction and information exchange at the beginning of the following session. Lockdown deprived parents of such support, and any questions they might have had on how to perform a given action or resolve an issue were left unanswered or restricted to phone calls, e-mail, etc., and were dependent on experts’ availability or willingness to help.

The stay-at-home directive reduced available informal support to phone/video calls or online messaging, which presumably lowered the quantity and quality of emotional support parents of children with DD usually receive from family members and friends. In addition,
they were left without tangible support, such as the possibility of leaving their children in somebody else’s care to run an errand or rest. Even in the case of something as simple as buying groceries, parents were faced with the dilemma of whether to bring their children with them or give up on the task altogether (in the case of children with serious disabilities, this would not have been an option regardless of the coronavirus). The new circumstances also introduced additional stressors, i.e. parents’ fear of their high-risk children with DD becoming infected, or fear of parents themselves becoming infected and being forced to leave their children owing to isolation or hospital treatment.

Most significantly children’s coping and reactions to the new circumstances may have served as the most powerful source of stress for parents. Children with DD are quite often sensitive to changes in daily routine (sometimes extremely so), and many of them may have experienced higher levels of anxiety and restlessness, which may have resulted in behavioural and self-regulation issues (e.g. more frequent and intense tantrums). As earlier research has shown that the maladaptive behaviour of children with DD is positively correlated with parental stress (Hastings, 2002), any deterioration in this aspect of their daily life during the pandemic may have resulted in lowered parental levels of WB and higher levels of anxiety or depression.

Finally, distance learning is likely the pandemic-related stressor that displayed the highest level of diversity from case to case. Although one could argue that online/TV school lessons were generally successful given the short notice with which they were prepared – and especially compared to the alternative of not having school at all – one must also acknowledge that it was not designed with a focus on children’s WB as a whole, but rather only one part of it: their right to receive an education. Governments implemented distance learning quickly, hoping that any mistakes or gaps would be resolved on the spot using feedback from teachers and schools. However, the entire concept was based on the general pupil population and not enough attention was paid to the specificities of children with DD. The “Action plan for the implementation of the distance education” published in 2020 by the Croatian Ministry of Science and Education (MoSE) states that:

[…] all principles applied in teaching and working with SEN [2] pupils in school, and included in current conventions, laws, and bylaws, scientific and expert recommendations are to be used in distance learning.

Guidelines provided only general information, e.g. teachers and professional experts involved in the education of children with DD were responsible for accommodating teaching materials to the children’s capabilities; a list of available materials was also provided, and the possibility of funding for assistive technologies was also noted (all links available in the Action Plan). Although these propositions may appear to be sufficiently specific and well-reasoned, in reality, teachers and parents encountered many practical problems not discussed in MoSE’s guidelines while implementing distance learning with SEN pupils. As the director of a vocational school stated in an interview for a local online news page (Gaščić, 2020), vocational schools are often neglected in various guidelines of competent institutions, leaving teachers and other involved parties in the school alone in their struggle to organise and implement adapted learning materials, as well as to resolve issues that arise during the learning process of SEN pupils (in this case distance learning). For example, it was impossible for some children with DD to attend lessons via computer, TV or either (e.g. visual impairment, children’s feelings of overwhelmedness, lack of internet connection/equipment), and additional efforts to overcome these obstacles were much needed to make distance learning possible and enforceable. These struggles were doubtlessly even more difficult and complex for the parents of such pupils, as in most cases, they had not been educated as teachers or trained to assist their child in the process. These parents depended on teachers’ knowledge, creativity, goodwill and readiness to invest additional time in preparing materials/tasks for their pupils. Also, the learning methods used in schools are mostly different from those typically used by
professionals during therapy, meaning that parents are usually less familiar with them. Therefore, some parents likely experienced problems with the materials sent by teachers, especially if the teacher insisted they be used (e.g. writing in pen while sitting at a desk instead of alternative methods, such as writing on a mirror); parents may also have had to make numerous additional adjustments in addition to those made by teachers. In addition, some children with DD usually attend classes with the help of a teaching assistant; the responsibilities of these assistants vary depending on the child’s educational needs, but the main point of their job is to assist the child’s learning process (MoSE, 2020). However, in the case of distance learning, parents of children who use such support were forced to juggle between the role of both teacher and assistant. Although MoSE did make it possible for teaching assistants to provide support in SEN pupils’ homes [3], this measure was rarely used owing to safety reasons (MoSE, 2020).

All of the aforementioned potential issues (and likely some others not mentioned here) undoubtedly led to higher levels of stress among parents of school-aged children with DD. This stress was presumably even higher when, e.g. a child with DD had problems in dealing with a lockdown measure, a parent had work-related responsibilities at the same time, a child with DD was finishing secondary school and preparing for the State Matura [4] or a parent had other children that needed attention and support. Although MoSE made a crisis team for psychological support available to all pupils, parents and teachers via phone or internet, the efficacy of this measure remains unknown; no information is available on how many times this service was used for psychological help, or by whom (i.e. if and how many parents with children with DD used it).

The extent of changes to our lives resulting from the COVID-19 outbreak is yet to be seen. However, in this review, we have opted to draw attention to issues faced by parents of school-aged children with developmental difficulties. As Bronfenbrenner’s (1979) model draws a connection between the development and prosperity of parents and children, the importance of this role is even more greatly emphasised in the case of children with, as they require additional support to overcome obstacles arising from their developmental difficulties and approach what is considered a typical developmental curve. Without such support, they stand no chance. Parents are the “wind in the sails” of children with DD. They serve as managers, organising all necessary medical treatment and therapy while simultaneously providing children with emotional support, love and inexhaustible faith. Given that they are key stakeholders in the lives of children with DD, it is important to provide parents with comprehensive formal support – even more so during the current pandemic or any similar extraordinary situation – to help them maintain their WB or at least lessen the impact of the current circumstances on their lives and daily functioning. This paper has provided an overview of the possible effects of the COVID-19 pandemic and the restrictive measures implemented to fight it; it may thus serve as a good starting point for governments in creating policy to cope with potential future pandemics or other unforeseen situations. One possible adjustment could be broadening available support to the health and social care system by, e.g. officially providing on-line therapy sessions with professionals; parents would able to ask questions and discuss specific courses of action and demonstrate or send videos of problematic situations they or their child with DD faced. This would potentially help them feel less alone and helpless; this is likely even more important for the sake of the WB of the entire family in question. Mental health support should also be formally underpinned with additional psychological support from experts familiar with the specificities of this population, as well as with the inclusion of other members of the primary family unit in treatment (e.g. siblings). As regards education, governments should consider parents key stakeholders when discussing and developing future documents (e.g. guidelines), bearing in mind that distance learning was not only problematic for SEN pupils but also a powerful source of stress and additional burden on their parents, which in turn may have led to lower levels of parental support and thus poorer results in educational tasks. In addition to this, problems that arose from distance learning
with children with DD required a somewhat different approach than those experienced by parents of typically developed children. This paper could also serve as a practical guideline for NGOs when planning and executing support that will ultimately be beneficial to children with DD, whether directly or indirectly.

This overview may also be informative to scientists interested in exploring the consequences of social distancing and school closures on the families of children with developmental difficulties. Building upon this knowledge may not only be beneficial to parents and children with DD but also to other individuals such as speech or occupational therapists (e.g. impact on their working motivation, burnout, communication with parents).

In conclusion, we would like to encourage the scientific community to further direct its attention to this specific population, as better insight and a greater understanding of how parents of children with DD are affected by the pandemic may have important practical and scientific implications, not only for the WB of parents but also that of children with difficulties and an even broader swathe of the general population.

Notes

1. From this point on, term parents with children with developmental difficulties refer to both biological parents and guardians, as individuals who play a parental role and provide care and support to a child with DD.
2. SEN pupils – Special Educational Needs pupils
3. To use this measure, both parent and teaching assistants were obliged to sign a written consent form.
4. The Matura (national secondary school exit exam) is obligatory for all gymnasium pupils after finishing their fourth year; it is optional for pupils of four-year vocational or arts schools who wish to apply to university (Central Government Portal, 2020).

References


Engelski/6/Action%20plan%20for%20the%20implementation%20of%20distance%20education.pdf (accessed 5 July 2020).


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