Introducing the COVID-19 crisis Special Education Needs Coping Survey

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Acknowledgements: The authors would like to thank first and foremost the participating families and family associations for their time and effort. We would also like to thank a number of people who have been instrumental in carrying out other research-related activities that have gone towards building this project: Sofia Arvaniti, Natalie Doppelt, Paulien Eijkeler, Lenka Hrnčirova, Diego Lopergolo, Zuber Mohammed, Maria Cristina Nedelecu, Danai Orlandatou, Evangelia Sarvani, Roberto Tadeau Iaochite, Angeliki Tampaki, Margarida Tomé, Pinelopi Xoundri and Alexandra Zaharia. This research was supported by the Swiss National Science Foundation (SNSF; P2NEP1-178584 for D.D. and PP00P1_176722 for A.S.) and the Research Funds of the Unidistance Suisse, Switzerland.

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Abstract

Individuals with special education needs have been particularly affected by the COVID-19 pandemic as they have been shown to be at high risk of losing medical and institutional support at a time when people are being asked to stay isolated, suffering increased anxiety and depression as a consequence. Their families have often found themselves under tremendous pressure to provide support, engendering financial hardship, and physical and emotional strains. In such times, it is vital that international collaborations assess the impact on the individuals and their families, affording the opportunity to make national and international comparisons of how people have coped and what needs to be done to optimize the measures taken by families, associations and governments. This paper introduces one such collaboration.

Keywords: COVID-19, anxiety, emotion regulation, special (education) needs, coping, international collaboration.
On the 31st December 2019, the World Health Organization (WHO) received reports of an unknown virus detected in Wuhan, Hubei province, China (WHO, 2019). This virus, primarily causing pneumonia-like symptoms, spread quickly across Asia and Europe with devastating consequences. Now named COVID-19, the disease spread widely enough to be characterized as a pandemic by the WHO on 11th March 2020 (WHO, 2020a). At the time of writing, there are more than eight million confirmed cases worldwide, and one reputable estimate puts the current death toll at over 435,000 individuals (Johns Hopkins School of Medicine, 2020).

But COVID-19 is not just a global health crisis: there have been significant economic, political, social and psychological repercussions. While the economic and political repercussions are discussed elsewhere (for example Gopinath, 2020; International Labour Organisation [ILO], 2020a; McKee & Stuckler, 2020; Organisation for Economic Co-operation and Development, n.d.), less has been mentioned about the social and psychological repercussions of the disease and how it has threatened the lives and livelihoods of many of the world’s most at-risk populations. While it is acknowledged that there is a real threat for migrants, refugees and the world’s poorest nations (Anderson et al., 2020; WHO, 2020b), it is critical that we highlight that people with special education needs have also been affected in most of the world’s countries (Clegg, 2020; Eshraghi et al., 2020; Jalali et al., 2020; Landes et al., 2020; Rose, et al., 2020; Toseeb et al., 2020).

While people with special education needs (SEN) can have a wide range of conditions and associated problems, and there are as many personal contexts as there are individuals, certain common characteristics can be highlighted. For example, while SEN is an umbrella
term referring to those who require assistance for disabilities that may be medical, mental, or psychological (for clinical diagnosis guidelines see American Psychiatric Association, 2013; WHO, 2004), it often includes specific neurodevelopmental and neuropsychiatric conditions such as autism spectrum disorder (ASD), attention deficit and hyperactivity disorder (ADHD), genetic syndromes with specific behavioural presentations, language disorder and intellectual disabilities. Almost by definition, people with SEN and their families need support to manage their condition: children often receive specialist support at their school (e.g. language therapy, behavioural therapy), whilst older people with SEN may frequent specialized support settings or community care facilities (if available). In some parts of the world, families may receive respite support during weekdays or weekends. In terms of their general health, people with SEN are more likely to suffer from somatic complaints, whether related directly to their primary condition or not (Samson et al, 2020; Tye et al., 2019), and also from mental health issues, particularly heightened loneliness (Margalit, 2010), anxiety and depression (Patel et al., 2018; Röhr et al., 2020) which may be the result of a change in routine. Furthermore, adults with SEN are more likely to either be unemployed, work voluntarily or be in low-paid employment (Gilson et al., 2018; Goldfarb et al., 2019), and it has been shown that SEN individuals are more likely to lose these opportunities in times of crisis (ILO, 2020b).

In short, people with SEN are at high risk of losing financial support in times of economic collapse, institutional and medical support at a time when people are being asked to stay isolated, and suffer increased anxiety and depression as a consequence of the COVID-19 pandemic. The families of people with SEN are likely to be put under massive and immediate pressure to provide the only support system for these individuals, engendering financial hardship, and physical and emotional strains.
This paper aims to give a brief description of the particular challenges and pressures that people with SEN and their families may experience across the world. It also highlights a new and growing international collaboration designed to better identify the specific stresses that people with SEN may experience due to the crisis, while also trying to understand how they and their families are coping within different countries. One of the ultimate goals of this collaboration is to provide an evidence base for governments, family support associations, individuals and researchers to assess the circumstances pre-, during, and post-pandemic, with the goal of positively influencing public awareness and public policy. This growing effort currently involves researchers based in 16 countries and participating families in over 70 countries and relies on a survey currently available in sixteen languages (Van Herwegen et al., 2020).

With a view to being as transparent as possible, an Open Science Framework site was created mid-March and the study was registered later that month, setting out these hypotheses and the statistical strategy to be followed to test these hypotheses (Van Herwegen et al., 2020). The public face of this collaboration is an Internet site that we hope will continue to provide a resource for individuals and relevant groups, associations and institutions from participating countries (https://www.specialneedscovid.org/)

The survey itself (Van Herwegen et al, 2020) begins with some general socio-demographic questions. These questions may in themselves prove revelatory as the prevalence and morbidity rates of COVID-19 are increasingly being linked to both living arrangements (urban vs rural), particularly in highly polluted areas (Wu et al., 2020), and to levels of poverty and socio-economic status, whether nationally (e.g. in England – Office for National Statistics, 2020) or internationally (Sumner et al., 2020). The survey continues with questions aimed at establishing the timeline of events and, in particular, to the time that national government guidelines were announced and how closely participants adhered to
those guidelines. Again, this is pertinent as, given the international nature of this
collaboration, the timing, the specific guidelines, and the adherence rates will be different in
each country and will therefore be a key factor in the analysis. For example, while all the
schools were closed in Spain and Switzerland, some schools in the UK remained open for
children with SEN, even during strict lockdown, although children with underlying health
issues (which often includes those same children) were asked to shield themselves and their
families. These obviously contradictory messages in the UK mean it is currently unclear how
many children with SEN actually continued to attend school, or on what basis families made
that decision.

The main body of the survey is dedicated to how people with SEN and their families
were coping at three distinct time points: before the pandemic began, when COVID-19 first
affected their country, and at the time the participant completed the survey. Questions about
the impact of the pandemic on families and how they are coping relate to specific themes
including health issues, social issues, financial, and housing issues, and issues related to
medical/education provisions and daily activities. Structuring the survey in this manner
means that we will be able to provide details about how people’s anxiety levels have evolved
on an individual basis, and in relation to their national and international contexts. Particular
attention is given to how individual people with SEN coped, and whether there was an
increase in anxiety symptomatology, specifically in restricted and repetitive behaviours. We
assume that COVID-19 has been anxiety-provoking for everyone who was aware of it, but
that people cope in different ways. We therefore included a section specifically about which
emotion regulation strategies the individuals and members of their families employed
(whether consciously or not), how often the strategies are employed, and how effective they
were. Emotion regulation is central to mental health and well-being (Gross & Jazaieri, 2014)
and the aim of the study is to gain insight into whether individuals with SEN from different
countries or with different disorders and conditions employed similar or different strategies effectively. The survey also contains open-ended questions asking participants to describe in their own words how their children dealt with stress. This additional qualitative information can help identify coping strategies potentially missed when relying on pre-defined items only. Participants were also given the opportunity to answer identical questions about a typically developing (TD) sibling, thus providing a built-in comparison group, automatically matched on social-economic status and other environmental factors.

Generally, we expect parents to be more concerned about the impact of loss of structure and routine for their child with SEN than for their TD children. Furthermore, we expect parents of children with greater health issues to worry more about the impact of COVID-19 regardless of the SEN group, and these families will be more likely to have self-isolated before their government recommended or required them to do so. Given that social and academic difficulties differ between some of the groups, we expect parents of children and adults with social difficulties to have been more concerned about the loss of social contact, and parents of children with learning difficulties to have been even more worried about the lack of school and education compared to children of other SEN groups or their TD siblings. Establishing which individuals and sub-groups were most affected by the current COVID-19 situation will allow authorities as well as those that provide support in terms of education and medical or wellbeing support, to allocate resources appropriately.

The current COVID-19 pandemic has had truly devastating consequences for a significant portion of the population but is likely to affect the lives of people with SEN and their families more severely than most. International collaborations and surveys such as this are of particular importance, not only to get national snapshots of how people are coping, but how that snapshot varies from country to country. The utility of such research in the immediate circumstances takes on particular significance as a second wave of infection
seems likely to occur and which, according to the director of the United States Centers for Disease Control and Prevention and others, may be worse than the current one (Sun, 2020). Indeed, experts at the WHO are now suggesting that rather than asking how to prepare better for the next time, we should come to terms with the fact that COVID-19 may be here to stay (BBC News, 2020; McElroy, 2020). As such, given that people with SEN are considered a particularly at-risk group, concrete scientific evidence of how they and their families are coping is not only essential, it is of immediate necessity.
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