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The Impact of COVID-19 on Children with Special Educational Needs and Disabilities and their Families

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30th April 2020

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For further information on the evidence this report is based on please see:

Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2020). How is COVID-19 affecting the mental health of children with Special Educational Needs and Disabilities and their families? <https://doi.org/10.31234/osf.io/sevyd>

Toseeb, U., Asbury, K., Code, A., Fox, L., & Deniz, E. (2020). Supporting Families with Children with Special Educational Needs and Disabilities During COVID-19. <https://doi.org/10.31234/osf.io/tm69k>

You can also find a lay summary of these findings in an article written for the *Times Educational Supplement*, published on Thursday 30th April 2020, found here: <https://www.tes.com/news/send-children-and-families-need-more-help>

Introduction

Since the first day of social distancing measures being implemented, our research group at the Department of Education, University of York has been collecting data from UK parents/carers of children with special educational needs and disabilities (SENDs). This ongoing data collection is allowing us to document the impact of COVID-19 on these children and their families over time. To date, we have collected data from over 450 parents or carers of a child with one or more SENDs. Data from the first 250 or so responses have been analysed and the findings are reported here.

We begin by describing the effect of COVID-19 on the mental health of children with SENDs and their families, as described by parents/carers. This is followed by parent/carer reports of how they would like to be supported during COVID-19. Finally, we make evidence-based recommendations about what needs to change or improve starting in the next three weeks and developing over the following six months.

How is COVID-19 affecting the mental health of children with SENDs and their parents?

Our initial analysis found that parents/carers described the impact of COVID-19 on their own and their child's mental health in six key areas. Two of these (**worry and mood, emotions & behaviour**) related directly to changes in mental health and wellbeing, while three provided perceived explanations for, or likely correlates of, those changes (**loss, knowing what is going on and feeling overwhelmed**). There was also a group reporting **minimal or positive impact** of COVID-19 on their own and/or their child's mental health.

We found that **worry** had increased exponentially for families and that, although some increase in anxiety is to be expected throughout society, the worries described were often related directly to being (or parenting) a child with SENDs. In many cases the anxiety was extreme and related to symptoms of SENDs e.g. excessive hand washing or concern around restricted food preferences. Parents were concerned that they did not have the knowledge to educate their children at home but, at the same time, were often reluctant to send them to school and risk exposing them to the virus. Changes in **mood, emotions and behaviour** were also reported, including a minority of children who had begun to display psychotic symptoms and suicidal ideation. As with worry, the level of distress described was higher than one might expect in non-SEND families. Some parents, disconnected from their usual sources of support and respite, appeared particularly distressed, vulnerable and in need of support.

In describing what was particularly challenging for them many parents wrote of the **loss** of routine, loss of support networks/structures, loss of specialist input and, in some cases, financial loss. The loss of carefully established routines appeared to be a particular challenge, possibly explained by 75% of our sample reporting an Autism Spectrum Condition (ASC). There was also a sense that children with SENDs were not having their needs addressed to the same extent as their neurotypical peers, and some resentment about this. Further challenge was created by the limited understanding and awareness that some children with SENDs have (**knowing what is going on**). In some cases this was reported as a protective factor but, for others, seeing life change rapidly and dramatically and not understanding why triggered distress and challenging behaviour. Finally, the challenge that

some parents reported was simply feeling completely **overwhelmed** by the need to meet their children's often complex needs without help. It was noteworthy that some families reported that COVID-19 had not affected their mental health and a minority reported tangible benefits. While positive, this generally reflected the sad reality that life is usually hard for these young people. For instance, being at school or going out to busy places can be highly anxiety-provoking, and for some of these families lockdown provides a welcome break.

What support would be helpful for children with SENDs and their parents?

Approximately one in ten parents reported that they did not require any further support or that the support they were receiving was adequate. The support needs of parents varied considerably and this is to be expected given the diverse range of needs covered by the umbrella term SENDs. The main types of support needs are described below.

Many parents wanted remote but regular and tailored **support from specialist professionals**, ideally those who usually support their child at school e.g. teachers, teaching assistants, speech and language therapists, and occupational therapists.

Parents wanted their child to receive **appropriate educational activities** that reflect their additional needs and some wanted support in explaining the lockdown to their child. Many children with SENDs do not communicate in typical ways and so alternative ways of communicating, such as **social stories**, were requested. In addition, parents mentioned the need for **materials or ideas for home learning** that are specific to their child's needs. For example, some children with SENDs use sensory toys and equipment in school that are not available at home. Parents also wanted their **child to see familiar faces**, even if just to say "*good morning*", to bring some sense of normality and alignment to previous routines. In many cases they also wanted to "*touch base*" with someone at school themselves, to make sure that what they were doing was appropriate.

Parents wanted **advice or support focused on their child's mental health and wellbeing**. Generic advice on children's mental health is not sufficient to support children with SENDs as the profile of mental health difficulties differs to that of neurotypical children. For example, disruption to routines has led to excessive anxiety for children with ASCs, in some cases leading to meltdowns and violence. Mental health advice aimed at neurotypical children will not suffice.

Parents described difficulties with food shopping during COVID-19, related to restricted food preferences and also the child's understanding of social distancing. A trip to the supermarket is not an option for families who cannot leave their child at home when the child will struggle to keep their distance from others. Parents therefore requested **help with food shopping** which could include priority access to online shopping.

Finally, many parents reported feeling overwhelmed with suddenly having to care continuously for their child with SENDs without support from external agencies. Parents mentioned the need for **respite care for the child** so that they could take a break. Some parents mentioned that they would like their **child to attend some sort of structured activity outside the home** (e.g. part-time school, play-group, weekend club etc.).

Evidence-informed recommendations – what needs to change or improve?

Our evidence suggests that children with SENDs and their parents/carers may have been negatively affected by COVID-19 to a far greater extent than their neurotypical peers and their families. While the needs of families with children with SENDs are diverse, our data suggests that **two** main changes/improvements, listed below, may help to alleviate some of these negative effects:

1. Provide support to schools, and school-linked health professionals, that makes it easier for them to provide remote, personalised support to children with SENDs.
2. Contact the most vulnerable families directly i.e. those with children who display very challenging behaviour or who have limited support e.g. lone parents, to assess and meet their needs. This may include practical support with day to day tasks or mental health support for the parent and/or child and will need to be tailored to individual families.

These changes/improvements will take time to implement fully but initial steps could be taken in the next 3 weeks and developed over the next 6 months. They will have resourcing implications as many school staff, and related professionals, are already thinly stretched as they work to provide remote learning to the majority of children and meet the pressing needs of those at immediate risk of harm in their own homes. There remains, however, a need to ensure that children with SENDs do not fall through the cracks, and that they and their families are supported over the coming weeks and months. Due to a higher rate of underlying health conditions among children and young people with SENDs it seems likely that a proportion of this group may need to operate in these changed conditions for longer than their peers, making a clear and practical focus on their needs an important and sensible investment now.