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My Son Can't Socially Distance or Wear a Mask: How Families of Preschool Children with Severe Developmental Delays and Challenging Behavior Experienced the COVID-19 Pandemic

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ABSTRACT

Background: Families of children with developmental delays (DD) prior to the COVID-19 pandemic experienced inequalities in accessing health and social care services. Measures put in place to combat the spread of the coronavirus have potentially exacerbated existing inequalities and have led to additional pressures for these families.

Methods: We carried out a cross-sectional online survey of parents of young children with moderate to severe DD and challenging behaviors living in England, UK. We asked about the impact the pandemic has had on their family well-being, receipt of support, and post COVID-19 concerns.

Results: Eighty-eight parents who are participants in an ongoing clinical trial (EPICC-ID) reported a broad range of challenges they faced during the pandemic: lack of information specific to children with DD; difficulties following social distancing and isolation rules; disruption or pause of health and social care services; deterioration in parental mental health and regression of the child's skills. Future access to services, negative long-term impact of school closures, parental unemployment were the parents' main post-COVID-19 concerns.

Conclusions: Families of children with significant developmental delays fear lasting impact of the pandemic on their own psychological and material wellbeing and on their child's health. These families require urgent help to meet major health and social care needs and should be prioritized within an overall children's mental health strategy.

The article includes a *commentary* from parents with lived experience.

KEYWORDS

COVID-19; coronavirus; pandemic; intellectual and Developmental Disabilities; developmental delays; challenging behavior; family; children; survey

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Introduction

The coronavirus (SARS-CoV-2) pandemic and the related restrictions have caused many challenges to health and social care services, economy, and wider society (Nicola et al., 2020; Pak et al., 2020). The negative consequences of the pandemic, e.g., deaths of loved ones, financial difficulties, unemployment, social isolation, and mental health problems have been felt by many people around the world (Brooks et al., 2020; Nicola et al., 2020). However, these might be more severe for families of children with Developmental Delays (DD) (Turk & McDermott, 2020). Children with DD at high risk of severe consequences of the COVID-19 infection due to a high prevalence of physical health comorbidities, but their families also require significant support from professionals to manage what is often high levels of need and barriers in accessing services (Emerson & Baines, 2011; Margari et al., 2013).

Closures of schools, day services, respite care, and other services implemented to slow the spread of COVID-19 will have increased pressure on families in providing the best possible care for children with DD. Social distancing and isolation measures have disrupted children's routines causing anxiety, emergence or deterioration of preexisting mental health problems, and challenging behavior. A survey conducted in Australia to capture the impact COVID-19 has had on older children and young people with disability including DD found that their needs were not met during the pandemic (Dickinson & Yates, 2020). Respondents reported cancellations of usual supports and education, deterioration of parents' and children's mental health, high rates of financial difficulties, inability to buy essential products (e.g., food and hygiene products) and lack of appropriate information about COVID-19 specific to this population group.

There is little known regarding how the COVID-19 pandemic has affected families of young children with DD (Rose et al., 2020) especially if they have additional mental health comorbidities and severe disabilities. In this paper, we report on a survey in one UK country (England) which investigated the experiences of families of very young children with moderate to severe DD and challenging behavior.

Methods

Sample and Setting

The survey items were generated using early published guidance relating to people with intellectual and developmental disorders and were discussed with coauthors including a member of a national charity for families of children with disabilities (Contact; <https://contact.org.uk/>). Prior to posting the survey online on the Opinio platform (<https://opinio.ucl.ac.uk/>), it was piloted with

three parents of children with DD and statements were amended in response to their feedback.

The survey included closed-ended and multiple-choice questions relating to family well-being, access to services and support, challenges specific to the pandemic, e.g., parents' experiences of remote consultations and post-COVID-19 concerns and a free text option regarding parent concerns about potential long-term consequences of the pandemic. The respondents were provided with a link to the survey starting with a brief paragraph describing the rationale for the survey and a declaration of anonymity, confidentiality and that participation was voluntary. If participants replied "yes" to a question about willingness to take part, they were then able to access the rest of the questions.

The survey questionnaire was distributed to 158 parents already taking part in the ongoing EPICC-ID multicentre randomized controlled trial (Farris et al., 2020) who had consented to be contacted for other research. The trial is testing the clinical and cost-effectiveness of Stepping Stones Triple P therapy for parents of young children aged 30 to 59 months with moderate to severe DD and challenging behavior in four sites in England, UK (North and South London, and the North East and North West England).

The survey was carried out between May and July 2020 and was disseminated via e-mail and text messaging. Either parent could respond to the survey and reminders were sent by researchers involved in the clinical trial in each of the sites. It was approved by the London Camden & Kings Cross Research Ethics Committee (nonsubstantial amendment 7, reference: 17/LO/0659).

Statistical and Qualitative Analyses

We used descriptive statistics to summarize quantitative information; decimal points are rounded off to the next nearest integer if greater than 5 or to the integer before the decimal if less than 5. We report responses where the parent has rated an item as very or highly relevant. Missing data are shown in the tables.

The free text responses were analyzed using inductive content analysis (Elo & Kyngäs, 2008). First, two researchers (AH and LP) independently read the qualitative responses to understand the data as a whole and employed open coding. Themes that were similar or semantically related were organized into subcategories, which were grouped into broader categories. The two raters reached a good agreement ($\kappa = 0.7$), measured using parameters proposed by Landis and Koch (1977). Disagreements were resolved by discussion and another author (KO) confirmed the final decisions made.

Results

Of the 158 parents invited to take part, 88 provided usable data, in that they answered any of the survey questions beyond demographic details. The

majority of respondents were mothers (95.5%), living outside London (51.8%), aged 35 – 44 years (45.5%), White-Any (61.8%), and currently not working (59%). One third (35%) of the parents reported having a high personal risk of severe consequences of COVID-19 infection due to underlying health conditions, in 16.7% there was active COVID-19 infection in the household and 12.5% were self-isolating (see Table 1 for more details).

Family Mental Well-being during the COVID-19 Pandemic

Many parents reported increased mental health challenges, in the form of stress (62.5%) and pressures (95.6%) from having to support their family

Table 1. Participant characteristics.

Characteristics	N (%)
Gender	
Female	84 (95%)
Age	
25– 34	33 (37%)
35– 44	40 (45%)
45– 54	14 (15.9%)
55– 64	1 (1%)
Ethnicity	
White – Any	55 (61.8%)
Black or Black British – Caribbean	1 (1%)
Black or Black British – African	14 (15.9%)
Asian or Asian British – Indian	2 (2%)
Asian or Asian British – Pakistani	3 (3%)
Other Ethnic Group	12 (12.6%)
Prefer not to say	1 (1%)
Location of residence	
London	40 (48%)
North East England	20 (24%)
North West England	23 (27.7%)
Settings of workplace	
Education	4 (6%)
Social care or other local government	4 (6%)
Private sector	8 (12%)
Voluntary sector	3 (4.7%)
Community or user-led organizations	3 (4.7%)
Healthcare	7 (10.9%)
Hospitality	7 (10.9%)
Does not work	28 (43.7%)
Current Situation	
Sick or self-isolating	11 (12%)
Working from home	10 (11%)
Mixture of workplace and working from home	5 (5.7%)
Mainly based at workplace	10 (11%)
Not at work	52 (59%)
Caring for other people (elderly or disabled people)	
Yes	12 (13.7%)
No	76 (86%)
High personal risk of severe consequences of COVID-19 infection due to physical health conditions	
Yes	20 (30.6%)
COVID-19 infection in household	
Yes	14
(16.86%)	

through the pandemic, whilst 66% of parents reported feeling less able to support their family because of deterioration in their own mental health. The majority of parents (88%) had to manage additional mental health problems in their child with significant DD attributed to their current circumstances. Loneliness (71.6%), lack of support from family and friends (56%) and increased family tensions (56%) were also rated highly relevant while a significant minority (15.6%) of respondents reported increased substance misuse and gambling (details shown in [Table 2](#)).

Access to Services, Support and Other Challenges

Before the pandemic, two thirds of families (66%) were receiving a range of supports or therapies including for mental ill health, social care, other parent support, accessed third sector services and community programs, various types of educational and respite placements for the child/children, although a small minority reported no services at all (13.8%). However, during the lockdown and into the early stages of easing restrictions, 90.9% of parents reported difficulties maintaining adequate support for their child and abrupt disruption of access to usual support from health services (76%), education (90.9%), social care, and voluntary sectors (71.7%). Many parents experienced disruption in accessing medical care for their child for both COVID-19 (67%) and non-COVID-19-related health problems (62.5%). Besides this, nearly three-quarters (70%) of parents had difficulties obtaining food, money, and other basic resources, and one in five (21.88%) reported staying in accommodation, they deemed unsuitable as it was lacking sufficient indoor and outdoor space.

“My five year old daughter has autism and her wellbeing is dependent on private specialist support and other outdoor activities that are no longer available to us. We are in a state of shock. My daughter’s mental health deteriorated significantly”.

Guidance on COVID-19

Ninety percent of parents reported a lack of relevant information to assist them in explaining the changes in routine to the child with DD. Over half of parents experienced difficulties in following government requirements on social distancing, self-isolation and/or shielding (58%), and implementing infection control measures at home (58.9%).

“Social Distancing. My Son Runs up to People and Touches Them”

“My son is severely autistic, so he can’t socially distance or wear a mask; we are not going out because of this”

Table 2. Family well-being during pandemic*.

	N (%)
Worried about me or my family getting COVID-19 infection	
Yes	57 (85.07%)
No	10 (14.93%)
Pressures resulting from the need to support my family through the stresses associated with the pandemic	
Yes	65 (95.59%)
No	3 (4.41%)
Increased difficulties for my family because of excessive needs	
Yes	40 (62.5%)
No	24 (37.5%)
Having to manage additional mental health needs for my child relating to COVID-19	
Yes	60 (88.24%)
No	8 (11.76%)
Feeling less able to support my family because my own well-being has suffered through the stresses of the pandemic	
Yes	45 (66.18%)
No	23 (33.82%)
Relapse and deterioration in mental health triggered by COVID-19 stresses	
Yes	37 (57.81%)
No	27 (42.19%)
Loneliness due to or made worse by social distancing, self-isolation and/or shielding	
Yes	48 (71.64%)
No	19 (28.36%)
Lack of access to usual support networks of family and friends	
Yes	51 (86.57%)
No	16 (13.43%)
Increased reliance on family/family tensions	
Yes	36 (56.25%)
No	28 (43.75%)
Increased drug and alcohol use or gambling	
Yes	10 (15.62%)
No	54 (84.38%)

*: response rates vary between n = 53–75; we present adjusted frequencies

However, over 70% of respondents also found information disseminated through the media and the National Health Service, England, as the most important sources of support during that time.

Use of Telehealth

The majority of parents (85%) had difficulties in motivating or enabling their children to engage in remote appointments. Furthermore, despite having access to technologies and equipment, many parents were dissatisfied with the use of video (40%) and telephone (43.7%) for assessments of their child's progress and receiving psychological treatment remotely. However, for almost half of the respondents (47%), e-mail and text messaging were preferred methods of keeping in contact with services.

Parent Concerns of the Future

There were 36 free text responses that illustrated a number of difficulties that those families faced and three main themes emerged which encapsulated the parents' worries about the short to medium-term future.

(1) Access to services.

Many parents reported they were concerned about funding and provision of services for children with DD and whether their child will be able to access health appointments that had been booked before the pandemic. Despite the lifting of restrictions, the National Health Service has yet to return to previous levels of activity. Nevertheless, online consultations remain available.

“My daughter’s appointment got canceled and I do not know when she will get her next appointment. This will lead to delay in interventions and that will have a long term impact on my child.”

(1) Education and health

Many parents were concerned about the impact home schooling will have on their child's development and progress. They reported that any skills their child may have gained had dissipated during lockdown and were concerned as to how they would make the transition to school or daycare facility after so many months at home. At the same time, they also feared sending their children back to school as they could not be certain that it was safe to do so.

“My daughter has regressed in behavior so badly and I worry that all the work on learning her to socialize would have regressed and getting her out to places once they open up”

“Just the kids missing school and friends and feeling stressed being in the house all the time, but we are happy to stay in as long as needed to stay safe”

(1) Going back to “normal”

This theme covers respondents’ concerns about employment, especially for those who may either have been unemployed or took part in the government job aid scheme. They were worried whether there would be opportunities for employment given the projected constriction of the economy and additive impact of further pandemic waves. They were uncertain about how returning to work across the country would be managed including their own anxieties about being infected with COVID-19.

“Cut to funding for special needs care, a second recession due to government bail-outs, shutting local charities due to lack of money, lack of respite due to this”

“We Will Never Get Rid of It”

“financially, future job prospects, social alienation, . . . future outbreaks as it will come back, really worried about my child’s social development skills . . . ”

Discussion

This paper presents results from a cross-sectional online survey that explored the impact of the coronavirus pandemic on families of preschool children with moderate to severe DD and challenging behavior in England, UK. Parents reported being under stress having to provide adequate support for their children when standard educational, healthcare and social care input was paused during the pandemic. Clearly, for some, the COVID-19 impact was felt acutely including having been infected and self-isolating though we did not seek confirmation of infection. Whilst several of these issues may be shared by families of children without DD, the respondents felt that the response to the pandemic did not fully consider the impact on children with significant needs who are very much dependent on additional supports beyond that of their parents. This is exemplified by surveys of the population at large that do not include intellectual and developmental disabilities (<https://www.ucl.ac.uk/news/2020/mar/new-study-psychological-and-social-effects-covid-19>) or do not include very young children with DD.

Considering that this population experienced significant inequalities in accessing inclusive education, health, and social care before the pandemic, it is likely that the response to the pandemic has made this gap even larger. Concern about the burden of care and the pause or disruption of services is shared by many who advocate for families of disabled children and echoed through other surveys of families with a disabled person (Disabled Children’s Partnership, 2020) and personal testimonies

(The Sunday Times, 2020). A survey of family and paid carers of children and adults with and without intellectual disabilities during the first pandemic lockdown (Willner et al., 2020) found that the former reported receiving less support and higher rates of severe anxiety and depression. Whilst our study is not directly comparable, most of the parents who took part reported high levels of stress and over half experienced a deterioration in their mental health.

It is of clinical relevance that parents did not fully embrace telehealth, reporting difficulties in including the child with DD in the consultation. Such technologies can be helpful and have been widely used for the assessment, diagnosis, and psychological therapy delivery (Hilty et al., 2013) for many years. However, it has also been shown that many populations including those with intellectual disabilities and their carers, may be subject to digital poverty that may hinder the full use of remote capabilities (Aref-Adib & Hassiotis, 2021). Therefore, the successful adoption of telemental health requires a degree of familiarization and enablement both for the professionals and the recipients. Many professional organizations are delivering such training (Royal College of Psychiatrists, 2020) to ensure effective communication and the establishing of a therapeutic relationship. It should also be incumbent on services to ensure that carers understand the benefits of such approaches and adapt consultations to suit different population groups including young children with DD.

Limitations

The survey presents the experiences of families of very young children with moderate to severe DD and challenging behavior as a distinct group. It is arguable that such families, who may also have other children, with or without disabilities, face particular difficulties in the nature or severity of need. The sample of this study was opportunistic as it comprised of parents who took part in the EPICC-ID clinical trial, and were willing to share their experiences. Fewer than half provided additional comments which may not be shared by all respondents. Therefore, it is possible that results of the survey might be not generalizable to all families of young children with DD across the UK. We did not undertake validity testing of the survey questionnaire and thus, the survey may not have captured all possible impacts of the pandemic on this vulnerable group. Finally, the survey respondents reflect the sample of the clinical trial and therefore, may not fully represent the voices of parents from Black Asian and other Minority Ethnic groups who we now know, are also disproportionately affected by COVID-19.

Conclusion

Parents of children with moderate to severe DD and challenging behavior face several adversities that may further compromise parental and child mental health and contribute to regression in the child's progress. Pause of in-person therapies and challenges in the child accepting or tolerating virtual instructions require new models of professional support. Our survey was carried out in a sample of parents of very young (preschool) children with DD which is rather rare in the studies that have been published so far (Willner et al., 2020). For such families, timely diagnosis and early intervention to both enhance developmental trajectories and improve behavioral outcomes are paramount (Aishworiya & Kang, 2020). Tailored care for those families including how best to utilize telehealth and adaptation of therapies for remote delivery to enhance parental and family wellbeing must be prioritized within a child's mental health strategy in response to the current and future public health emergencies.

Lived Experience Commentary by Nikki Kimber, Rebecca Scurr and Ilham Elfenne

As parents of children with developmental disabilities, we can relate to the points mentioned in the paper. Hardly surprising we have all found it so hard when absolutely everything was turned off like a tap. We have always felt ultra-cautious too as there were concerns about patients with developmental and intellectual delays that would be prioritized for treatment of COVID-19. Whilst this is not a major concern reported in the survey, believing that your child may not have been offered a ventilator or treatment in hospital, only palliative care at home from a distance, certainly made families retreat even further into their “bubble.” We felt that the support that was offered did not provide the skill and resources needed for children with developmental delays. Watching the news for updates increased our feeling of being “outcasts” as there was no information about families like ours.

The prospect of a young person or a family member with caring responsibilities contracting COVID-19 would have many added complexities and fears for the child with developmental delay. There would be no real support because as the study highlights – that was all stopped.

Our personal experience with our children also highlighted just how important friendship networks are and how hard it has been in giving them the access and experiences they enjoy with their friends. For many children with developmental delays, it is impossible to recreate those experiences through text, face time, zoom calls, e-mails, and letters. Therefore, they are cut off from their social group. This, in our experience, can have a profound effect and can genuinely make children sad.

As parents of young people with significant disabilities, we become very tuned in to our children and the majority of the time we can solve their problems for them. During these unprecedented times all of the tools we possess to maintain the role of “problem solver” have been removed and the resulting frustration and challenging behavior has been exceptionally tough to live with. We are all together in the same space for a long time and the answer to every question and request seems to be no! We can imagine how hard that is when the young person you are with has no idea why the answer is no when they have always done something before. The key success of the pandemic was embracing remote working; however, this may not have extended to young people with developmental delays and their families.

Conditions may be brighter as lockdown and shielding are over but many of the initial worries about treatment and support are still at the forefront of our minds; we cannot say it has got any easier.

Disclosure statement

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