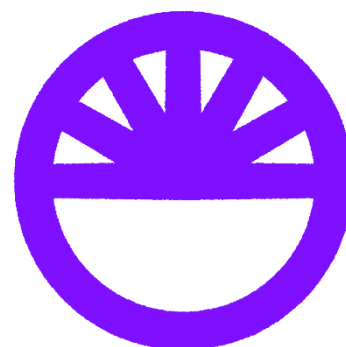


# Lockdown isn't over for us all:

## Co-produced policy recommendations for supporting parents and carers of children with additional needs beyond Covid-19 and through the cost-of-living crisis



Rosalie Warnock, Geoff Page, Ruth Patrick, Jim Kaufman, and Stephen Kingdom

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### Summary

This short report sets out some of the specific ways in which the Covid-19 pandemic has impacted low-income families who have children with additional needs. Drawing on participatory research with Covid Realities participants, combined with survey data from the Disabled Children's Partnership, the report sets out two participant-led policy recommendations: better support for parent carers, including respite care; and better mental health support for children with additional needs and their parent carers. Noting the additional challenges wrought by the current cost-of-living crisis, the report calls for a more caring and compassionate social security system for some of the most vulnerable children and families in our society.

### Introduction

Living with a disability is expensive. Not only are parents and carers of children with additional needs more likely to be unable to work (or work full-time) due to their caring responsibilities, but families of disabled children spend on average £581 more per month than families who have non-disabled children (John et al., 2019). This is due to higher

costs associated with specialist food, equipment and toys, higher utilities costs (due to time spent at home, or bathing/laundry requirements), higher transport costs (if relying on a private car or taxi services) and sometimes, higher housing costs (due to a need for more space).

Households that contain children with additional needs therefore also face a higher risk of poverty (Joseph Rowntree Foundation [JRF], 2020). According to the Family Fund, a national charity working with families with disabled children, the average household income of a family with a disabled child is just £17,000 per year (2002, p.4). On average, they report that that income has fallen by £400 over the past year, while household bills have risen on average by £800 per year over the same time period (Ibid, pp. 4-5). These figures highlight the additional costs of the Covid-10 pandemic for families with children with additional needs (Contact, 2021) and additional challenges that the cost-of-living crisis poses for these same families (Family Fund, 2022).

Families of children with additional needs have not only faced particular risks and challenges *at the height of* the Covid-19 pandemic but continue to face specific risks and challenges as the UK has phased out its Covid-19 rules and restrictions (Contact, 2021; JRF, 2020; Lunt, 2021; Warnock, 2021). While Covid-19 continues to mutate and spread, it still poses a deadly risk (albeit dampened by vaccination programmes) – particularly as we approach winter. Importantly, then, lockdown isn't over for many families, where vulnerable children or adults still need to shield or remain vigilant (Contact, 2021; Disabled Children's Partnership, 2020, 2021). While many of us returned to big supermarkets, public transport, and seeing friends and family from summer 2021, those still isolating must continue to deal with the higher - and now rising - costs of expensive food deliveries, utility costs, home-based entertainment. Additionally, for parents of shielding children with additional needs, they must also manage the continued emotional pressure of full-time care, often without respite.

This short report responds to an urgent need to ask parents and carers of additional children *directly* how the Covid-19 pandemic has shaped their immediate and longer-term policy demands with regards to supporting their children. We share participant-led recommendations for change recognising that the cost-of-living crisis makes meeting these needs both more challenging for policy makers, yet even more critical for families than ever before.

[Covid Realities](#) was a participatory, collaborative project led by the Universities of York and Birmingham in partnership with Child Poverty Action Group and funded by the Nuffield Foundation (with support for this piece of work from the Social Policy Association and Disabled Children's Partnership [DCP]).<sup>12</sup> Between July 2020 and June 2022 we worked with parents and carers on a low income across the UK to document life during Covid-19, via online diary entries and monthly "Big Ideas" workshops. Of the 135 parents who have left online diary entries, 17 (12.5%) mentioned having a child with additional needs, including autism, sensory issues, chronic lung disease, learning difficulties and diagnosed and undiagnosed mental health needs. This report therefore uses the language of "additional needs" to refer to a broad spectrum of physical and intellectual disabilities, chronic or life-limiting illnesses, neurodiversity, and mental health needs.

In practice, many parents left relatively few diary entries, sometimes focused on just one or two topics (or in direct response to a specific question posed by the research team). The 12.5% of entries mentioning caring for a child with additional needs consequently represents the lowest possible threshold, and it is likely that many more participants were living in similar situations. Their accounts add a qualitative understanding to the statistical evidence that exists on low-income families' experiences of the pandemic (as published, for example, by the Covid Realities team and Special Interest Group partners<sup>3</sup>).

While 90% of low-income families reported spending more on essential bills while children were at home at the height of lockdown including on food, utilities and technology (Brewer et al., 2021), some Covid Realities participants reported specific pandemic-related challenges caused by their children's additional needs, for example, around food costs. Others reported that their children had been too anxious to go outside. Still others had at-risk children who have been forced to shield long-term. While the height of the pandemic appears to be behind us, responding to the difficulties it threw up – and which sometimes still remain – for families with children with additional needs, requires a proactive, sensitive and empathetic policy response.

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<sup>1</sup> The follow-on project to Covid Realities, [Changing Realities](#), is now live.

<sup>2</sup> The [Disabled Children's Partnership](#) (DCP) is a major coalition of over 90 organisations which campaigns for improved health and social care for disabled children, young people, and their families.

<sup>3</sup> The Covid Realities project led on a [Special Interest Group](#) of 14 projects, all working to research the impacts of the Covid-19 pandemic on low-income families. A full list of partner projects, with links to their project websites and findings, can be found via the link above.

The findings shared in this report are drawn from Covid Realities diary entries (July 2020 – September 2021), a participatory Zoom event with nine Covid Realities participants (November 2021) who have children with a variety of additional needs, and Disabled Children’s Partnership [DCP] survey data and reports (2020, 2021). The policy recommendations outlined here were developed in conjunction with Covid Realities Zoom participants (with facilitators from the Covid Realities project and the Disabled Children’s Partnership). The report proceeds in four sections. The first sets out the contextual reasons why children with additional needs and their parents/carers may have found the Covid-19 pandemic particularly challenging. The next two sections set out participants’ immediate policy priorities: better support for parent carers, including respite care; and better mental health support for children with additional needs and their parent carers. The report concludes with a call for a more caring and compassionate social security system for some of the most vulnerable children and families in our society.

### “It’s impossible”: Life During Lockdown

Families with children with additional needs experienced the height of the Covid-19 pandemic and associated lockdowns in a variety of ways. Some parents found lockdown difficult, reporting that their children struggled to understand why they couldn’t go outside or see friends and family:

“My children can’t see their grandparents. One [...] has special needs and doesn’t understand we have to stay in unless going out for shopping.” (Allie)

While others reported that the slower, quieter pace of life – often linked to school closures – suited their children:

“During lockdown I was able to take my daughter with autism out more. We went to the beach which is nearby where she felt safe as we were the only ones there. She picked up the tiniest of shells. We embraced the sound of the waves. We watched the heron fish in rock pools. We watched the patterns in the sky made by a flock of seagulls.” (Alex)

School closures were a particularly mixed bag for families. Some parents, like Rosie, explained that while her autistic daughter enjoyed being able to set her own routine at

home, her elder, neurotypical daughter struggled with the disruption to her education. Rosie had to manage the competing needs of both her daughters, and her younger son:

“The new lockdown brings a real mixed bag for our family. My [autistic] daughter (14) is relieved that she doesn’t have to face attending school. She enjoys having learnt to structure her time at home and she is less anxious because she doesn’t have to deal with the difficulties that arise with other pupils not social distancing and following rules. She is pleased that there are clear rules and doesn’t feel pressured to go out anymore. For my eldest daughter (17) lockdown brings worries about her college studies and university applications. My youngest (8) takes everything in his stride but as my husband is a key worker, I am left to ensure home schooling is being done.” (Rosie)

Rosie’s comments remind us that while most families had to balance the competing pressures of work, domestic maintenance, child-care and home-schooling, those who have children with additional needs will also have had to factor in the impacts of the pandemic on their children’s specific needs and responses to the pandemic, lockdowns, disrupted routines and associated uncertainty (see also Contact, 2021; DCP, 2020). Teddie, juggling similar complexities, elaborated:

“Trying to parent 5 children of which 4 have additional needs all different and all having their own challenges is hard - add to this lockdown, changes in routine, sometimes no routine, and then add on winter - it’s impossible.” (Teddie)

Unsurprisingly, then, parent carers participating in the zoom session had two main short-term policy demands: better support for parents, including respite care; and better and immediate access to mental health support for both children and parents.

### *Policy recommendation 1: Support for parents, including respite:*

“What help has there been for parents with kids with additional needs?” (Georgie)

At the height of the pandemic, Georgie’s daughter was already on a diagnostic pathway. But during the early stages of the Covid-19 lockdown, most face-to-face support services were halted entirely (Hill, 2020; DCP, 2020). During this time, support for children either going through diagnostic processes (via the Children and Adolescents’ Mental Health Service) or assessments for Education Health and Care Plans (via local authority SEND

services) often stalled. For Georgie’s family, her daughter’s lack of diagnosis also meant the family couldn’t access the respite care they hoped for, either. Their situation was far from unique, with other commentators highlighting the challenges children and families faced as local authority SEND services were given permission to relax statutory timeframes for responding to calls for help at the height of the pandemic (Tirraoro, 2020).

Newspapers reported parent carers with diagnosed and undiagnosed children with additional needs feeling on ‘the brink of collapse’ (Hill, 2020) as they tried to cope without the respite care which ordinarily would give them a break and allow them to manage the rest of the time. Instead, the burden of care fell not only on parent carers, but also on siblings, who had to step in to help their parents out (Carers Trust, 2020; Hill, 2020). Covid Realities participants recognised these findings, but thought they fell some way short of recognising the full extent of the problem. As one Covid Realities participant put it:

“We’re the captain of the ship. If we [parents] are not ok, then nothing’s going to be ok.” (Zoom participant, Nov 2021)

Children receiving Disability Living Allowance (DLA) at middle or higher rate can access funding to pay for activities, or respite carers, via the Short Breaks programme<sup>4</sup>. Parent carers may also access both hourly and residential respite care via children’s social services, although often, not without a fight (Warnock, 2022). But caring is mentally, physically and emotionally hard work – even without a global pandemic and repeat lockdowns. Explaining why they needed more support in general (i.e. not just during the pandemic), one Zoom participant said that they felt ‘on the brink of crying all the time’, and another said that they always felt in ‘emotional deficit’.

If parent carers are going to be able to look after their children as they want to, while also looking after themselves, pathways to respite care and other forms of support must be simplified, widened (extending eligibility) and broadened (in scope, extending the amount and types of care, including respite care, available to each family). Parents and carers should be given clear and constructive guidance on what support is available and how they can access it with the least amount of extra paperwork possible.

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<sup>4</sup> This is a national scheme, administered by local authorities.

## *Policy recommendation 2: Better mental health support for children with additional needs and their parents/carers*

When it became apparent that the UK wouldn't just see one short, sharp lockdown, commentators began warning of the mental health impacts of the Covid-19 pandemic - particularly on low-income children and families (see for example Edwards et al., 2020). In a survey of 4000 parent carers of children with additional needs in May 2020, 71% reported that their child's mental health had worsened since the start of the pandemic (DCP, 2020). Some children with additional needs struggled more than neurotypical children might have done with disruption to routines, following changing social "rules", repeat lockdowns, and a general sense of uncertainty (Contact, 2021; DCP, 2020) Not all children - due to age, disability, or both - understood what was going on at the height of the pandemic. With face-to-face therapies withdrawn or moved online, not all children had access to the mental health support they needed to try and process these sudden and unpredictable changes.

Another participant, David, reported that his autistic son ate more than usual, due to stress and anxiety caused by the pandemic and disrupted routines:

"My spending has increased due to covid, our food bills have gone up due to our children being unable to go out they are eating more due to boredom. My eldest son who is autistic is eating more due to stress. So our expenses have gone up."  
(David)

Additionally, while children may have struggled to process the changes around them, their parents and carers often also struggled not only to support their children's responses to the pandemic, but also with their own concerns for clinically vulnerable children:

"Both of my daughters were born extremely prematurely and with chronic lung disease. We went into the pandemic with oxygen canisters for them and now [the canisters] have been removed I still feel extremely anxious about what may happen if they catch covid. It's very very hard to parent in such difficult circumstances. I'm always praying for brighter happier days." (Fiona)

Research conducted at the outset of the pandemic showed that 54% of parents of children with additional needs reported that their own mental health had worsened, just in the two months into the Covid-19 pandemic (DCP, 2020). In June 2021, the DCP



published the findings of their longitudinal survey of parental wellbeing (Jan 2021 – Jun 2021) and found that, not only were parent carers' baseline levels of stress higher than the general population, but that 56% of respondents were also experiencing the same or worsening levels of stress by June 2021 as Covid-19 restrictions were lifting (DCP, 2021). This shows not only the cumulative impacts of the pandemic on already chronically stressed parent carers, but how the easing of restrictions was itself a major source of concern for parents with clinically vulnerable children.

Mental health support in the UK is chronically under-funded relative to demand. In August 2021, *The Guardian* reported that there were 1.6 million adults on the waiting list for NHS mental health support, and a further 8 million adults who had been told they did not qualify for support because their needs were not “great” enough (Campbell, 2021). The charity *Young Minds* runs a parents' helpline to support parents and carers supporting young people with their own mental health difficulties. They reported a 48% rise in demand for that helpline between 2019 and 2021, reflecting the demands of the Covid-19 pandemic on children and young people (Young Minds, 2021). Not only then are parent carers struggling to access mental health support for themselves, but they clearly need more help to support their children's mental health, too. Demand for this support will only grow as the cost-of-living crisis continues to bite. Children and Adolescents Mental Health Services (CAMHS) has been known to be chronically overloaded for years. In January 2020, prior to the Covid-19 pandemic, a survey found that 43% of GPs were already recommending that parents pay for private mental health support for their children if they could, because CAMHS waiting lists are so long (Campbell, 2020). There are huge disparities in wait times for CAMHS services across the UK, with some children waiting up to three years to be seen (Tidman, 2022). Additionally, not all CAMHS services are suitable for children with additional needs, who may need to wait longer or travel further to access specialist CAMHS disability services.

If parent carers are going to be able to look after their own mental wellbeing, while supporting their children's mental wellbeing, both parent carers and children with additional needs must be able to access specialist mental health services in a timely fashion. One suggestion amongst health professionals is to uniformly extend access to CAMHS until 25 years (rather than 17 or 18 years) so young people have time to access it before being transferred into adult mental health services (Crenna-Jennings and Hutchinson, 2020). Major investment into both IAPTS and CAMHS is desperately needed,



plus further investment in specialist services and therapies appropriate for supporting children with additional needs and their families.

## Conclusion

This report has highlighted some of the specific challenges that the Covid-19 pandemic has wrought on low-income parent carers of children with additional needs. Drawing on Covid Realities participant diary entries, a participant-led Zoom session, and findings from the Disabled Children's Partnership, the report sets out two immediate policy foci. The first is better support for parent carers, including respite care. The second is better mental health support for children with additional needs, and their parent carers/other family members. The Covid-19 pandemic has shone a light on ongoing problems and a lack of support: how challenging caring for a disabled or neurodivergent child can be for parent carers – and the additional ways in which the pandemic made this harder. Parent carers have made it clear that they need additional, external help if they are to be able to support their children to the best of their ability. It is a mistake to think that Covid-related risks and problems have gone away, especially for vulnerable groups such as children with additional needs and their families. This is doubly important in the context of the current cost-of-living crisis. Covid Realities Participants' demands – for readily available, high-quality, adequate respite care and mental health support (IAPTS and CAMHS) – rest alongside a longer-term desire to see a kinder, compassionate social security system which supports some of the most vulnerable families in our society.

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