

The experience of children with disabilities and their families during the COVID-19 pandemic; what lessons can we learn?

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Abstract

COVID-19 has had serious, negative impacts on children's health and development. But the impacts have not been felt equally; disabled children and their families have been hit particularly hard. In this paper we summarise UK legislation to limit the spread of the virus and describe how services to disabled children changed as a result. We discuss the long-term deleterious impacts of changes in service provision on the health and wellbeing of disabled children and the parent carers supporting them. We close with lessons learned for resetting services to support the ongoing recovery of children and their families and recommendations for delivering services better in future emergencies to ensure that disabled children's health and wellbeing is maintained.

Keywords

Children, disability, family, services, COVID-19, pandemic, experience

This paper describes the impacts of UK legislation to reduce the spread of COVID-19 and the changes to services on the health and wellbeing of disabled children and their parent carers.

UK Response to COVID-19

On 23rd March 2020 the UK government issued the Coronavirus Act to limit the spread of COVID-19. The Act enforced a national lockdown with a stay-at-home order for everyone except keyworkers. Most of the UK population was allowed out to shop for essential items and to exercise outdoors for up to one hour a day. Schools were closed to all children except those of key workers, children with Special Educational Needs and Disabilities who had Educational and Health Care Plans (EHCPs), 'vulnerable children' and those on the child protection register. Many non-essential health and social care services across the country were paused. This included elective surgery, outpatient visits, community services and short breaks. Some areas struggled to treat the rapidly rising number of people, mostly adults, with acute disease and staff, especially physiotherapists, speech and language therapists and occupational therapists, were redeployed from children's services to adult acute wards.

In May 2020, the initial lockdown was lifted but social distancing measures were maintained. Those who were deemed extremely clinically vulnerable to the COVID-19 virus were advised to continue to 'shield' by staying at home and avoiding face-to-face contact with people outside their immediate household. Non-essential health and social care services resumed, and a phased reopening of schools commenced in June 2020. From September 2020 'support bubbles' allowed two households to support each other if one contained a child under two years or a disabled child up to five years of age who needed continuous care, and in November 2020 'childcare bubbles' enabled friends and family from another household to care for child under 14 years. Further waves of the COVID-19 virus led to further national and local lockdowns in late 2020 and early 2021. The national vaccination programme commenced in December 2020; and by May 2021 over 47 million adults had received two doses of vaccine. Restrictions on legal limits on social gatherings were eased from March 2021 and all restrictions were lifted in England in July 2021.

Impacts for Children and Families

Although children faced lower risks of mortality and morbidity from COVID-19, they were badly affected by school and childcare closures and social restrictions. Being unable to socialise with people outside their immediate household or to visit places outside their homes curtailed their opportunities for play and for developing socioemotional, language, cognitive and motor skills. In late 2020 and 2021, rates of school readiness were lower for children entering school after lockdowns and those in school were more likely to be behind in their learning. Rates of anxiety in young people also increased (1) and school attendance rates have plummeted since the pandemic. Despite coronavirus being judged 'the great equalizer' and UK government sentiment that 'we're all in this together', its effects have been far from equal. The impacts of COVID-19 have been greatest for families living in poverty and social disadvantage and widening existing gaps in children's education, health and socio-economic outcomes (2).

Whilst the effects of the pandemic have been hard for families of typically developing children, families of children with special educational needs and disability (herein disabled children) have been some of the hardest hit. Early in the pandemic, parent carers reported feeling abandoned as

the multi-disciplinary health, education and social care services they relied on for support were restricted (3). Given that disabled children are more likely to grow up in single parent households and in poverty, the impact of social restrictions and service loss was harsh for many families. When services re-opened, they often did so with fewer staff than before the pandemic, due to illness, continued redeployment and staff leaving their posts. Reductions in the available workforce depleted services that were already stretched, coming on top of a decade of service cuts due to austerity, meaning that services needed to be redesigned to cope with unprecedented level of need with less resource.

The Resetting Study

In 2021 the National Institute for Health and Care Research Policy Research Programme commissioned the [Resetting Services to Disabled Children study](#) to learn lessons from the pandemic to help reset services to disabled children and plan for future emergencies. The study aimed to understand how services to disabled children changed during the pandemic, what changes had worked well in continuing support children's health and wellbeing during a time of emergency, and what had not worked well and why. We reviewed published research on the impacts of changes to services for disabled children worldwide. We worked with families and teams from five Local Authority areas of England that varied in their degree of urbanisation, area deprivation, the languages spoken and the number of organisations providing health, education, and social care services to children, to find out about local changes. Across the five areas, we interviewed 78 health, education and social care professionals (including 6 commissioners, 28 service leads, 18 therapists, 6 paediatricians, 2 surgeons, 3 nurses/ health visitors, 4 psychologists, 5 head teachers / special educational needs coordinators); 48 parent carers of disabled children (45 mothers and 3 fathers), whose children had a range of diagnoses, including autism, ADHD, cerebral palsy, genetic conditions, and epilepsy; and nine young people with neurodisability conditions (aged 8-16 years; 8 males, 1 female). The impacts of the pandemic described below are extracts from the qualitative study and the review of literature.

Changes to Services for Disabled Children

Implementation of national guidance

During the first phase of the pandemic in the UK, coronavirus legislation was frequently updated. Early guidance often did not refer to children and guidance sometimes differed across sectors. Commissioners and senior managers across health, education and social care struggled to interpret guidance and to keep pace with the service changes that were required with shifting resources as staff were redeployed to acute services to cope with changing number of cases locally. The lack of consistency in guidance across sectors and the degree of interpretation required led to variations in how services were provided across organisations supporting the same families.

All the paediatric guidance we had to interpret and decide well, it was adult acute. So, we had to interpret it for Community situation. So, it was so frustrating. There's just this assumption that people only work in hospitals with adults. Completely infuriating. A1S_014

Keeping families informed of changes to services

At the start of the pandemic services tried to contact individual families, to check children's level of need and to describe the services that could be offered. They also instigated multiple methods of relaying information to families, such as newsletters, announcements of websites and social media. But still many parent carers felt "cast adrift" (AP4_014), unsure of what services were available and where to go for help. They sought information from other sources, including news organisations, and heard messages about the prioritisation of services and the need to keep health services free to focus on acute care. Some parent carers did not get the letter advising them to shield their child they expected to receive. Others received a letter but did not agree that their child fitted the criteria for shielding. Parent carers also reported receiving conflicting advice from school and from their health professionals, especially on whether their child should attend school in person. Without clear and consistent sources of advice, parent carers were forced to make complex decisions about whether to send their child to school and to allow visits from health and social care practitioners. During 2020 rates of emergency care attendance reduced for children, suggesting that urgent health conditions may have gone untreated.

Her diagnosis is epilepsy and severe learning disability. Aside from that, physically she's very well. She deals with viruses very well, so I kind of viewed her as a typical child. I very early on researched whether she was at high risk, and it was deemed that she wasn't, so I was quite relaxed in that regard. What we, I think we probably could have, in those early days, justified my mum, who is another carer for (Daughter) and supports us, coming to visit us. But we didn't, because I was nervous for her and what the pandemic meant for her. (Grandmother's) in her 60s and is very fit and well. But I just didn't want to take that risk. We questioned the school and we pushed for (Daughter) to have a place. I probably would have pushed even harder had I felt less nervous about the virus because of course I feel like, you know, I'm a responsible citizen. The last thing I want to do is put any vulnerable children at risk. You know, I don't want to force the school into doing something that they shouldn't, or they didn't feel comfortable doing, but equally I knew very clearly that (Daughter) qualified for a school place and I could not understand why with the level of need she had, she wasn't prioritized within that school environment. A1P_003

I was panicking, because I was thinking if (child) got it, there's no way I could get him to a doctor. Not that he should go to a doctor, but if he got it really badly that you know, there was that whole, do not resuscitate thing with people with disabilities, which, and yeah, there was all that sort of thing. That was very worrying. A1P_012

Interdisciplinary working

Providers rated each disabled child's need for services on a red, amber, green system (RAG rating), where red indicated children most at risk and face-to-face contact was still required and amber and green indicated reducing risk without the need for face-to-face contact. When the Control of Patient Information (COPI) notice came into force in June 2020, services were allowed to share concerns about individual children. This meant that staff could work in a more interdisciplinary way, addressing not only the concerns that came under their professional remit but also collecting information about other domains that they could either address themselves or relay to their colleague. They began to adopt an 'Every Contact Counts' approach in which each contact with a family covered multiple child health and development domains. But many disabled require specialist intervention from multiple practitioners and interdisciplinary working was not always a safe option.

You know, we used each other as much as we physically could, and we all did things that we don't normally do in our professional skill set to kind of, try and put that child in that family at the front. A5S_004

Telehealth

Telephone and video conferencing appointments allowed most professional groups to maintain contact with families and worked well to review medications and to monitor known health conditions that parent carers could describe and that practitioners could see on screen. However, telehealth was less successful for assessments and interventions that require touch or active involvement of the child with scaffolding of activities and feedback for skill acquisition.

I asked Mum to do all these things with this baby on the video. And uhm, what we saw three months after really surprised us. So, there was a developing CP (cerebral palsy) which if I'd been able to handle this baby, I would have felt in the tone. But it wasn't coming across in the way. This baby was moving on this video A2S_004

Many therapists found it difficult to devise interventions that could be completed within the home or that would appeal to children, keep their attention, and could be completed on screen whilst either the therapist on screen or the parent carer scaffolded activities for children's learning. These difficulties with teletherapy left children without or with low levels of therapeutic interventions needed to maintain their pre-pandemic levels of health and promote their acquisition of new skills.

I think more specific speech type work again was more difficult, and especially with children where their attention and listening was limited. I think in the clinic environment you can pull out all the stops to keep them focused on the task. But on video umm, people found that more difficult. A4S_20

He's (AHP) like, "Well, I can do video or telephone" and he (AHP) said "or I can send him (son) some little videos to watch of what he needs to do". And I said because he's, they're not, he's not gonna engage. It's really, really difficult. And he (AHP) was like "well you're just going to have to try". He phoned about three more times, every week or every fortnight. And I'm like, he's still not gonna engage. It's not happening. And he's like, he was like "I'm gonna close the referral if you need them in the future, you'll have to go back to your GP." AP3_012

Impacts of Service Change on Child Health and Wellbeing

Social restrictions and circumscribed leisure activities, often within a family or 'bubble', restricted many children's physical, emotional and psychological development. Conditions that would have been addressed by universal or targeted intervention required specialist help by the time children could be seen.

We put a lot on hold with our health visiting and our, particularly one- and two-year checks. And actually, when we've reopened services more fully now and direct and seeing children physically, you know we are noticing those children who have got, you know, physical physically. Yeah, gross, gross motor delay language delay. In fact, motor delay more than language delay, interestingly some children improved with language because they were actually being spoken to in the home 'cause they had no choice. But gross motor delay in particular was something we hadn't anticipated, but that has definitely been an issue. A2S_FG07

Loss of early years services also meant that some neurodisability conditions were diagnosed late.

We had a couple of cases of babies where parents presented them into ED cause one of their limbs wasn't working properly and they'd had neonatal strokes that hadn't been picked up..... And they would have been [pre-pandemic] picked up by a health visitor. A1S_012

Children who were receiving specialist services at school lost access to their usual activities and the assistive technology that allowed them access to learning and independence, such as sensory rooms and hydrotherapy. Parent carers tried to keep up with therapy programmes but struggled without the necessary equipment and prior teaching on how to implement techniques. Previously well-managed conditions such as worsened without regular specialist input. For children with neurological conditions causing spasticity and dystonia loss of input often led to pain, contractures required invasive intervention and in the worst cases meaning that surgery was no longer possible.

Yeah. I think for those children who need postural management, then it's knee contractures and hamstring contractures. So when we did get back to school children lost standing postures, stopped being comfortable to stand. A1S_014

Increases in anxiety, distress and challenging behaviours were reported by many parent carers and have contributed to significantly increased numbers of referrals to child and adolescent mental health services and to increased rates of school absences since the pandemic (4).

He became very anxious. He did a lot more stimming and things because he didn't know what was going on. And we could see our child very stressed and anxious and not able to communicate. A3P_015

Children were also at greater risk of harm when socially isolated. The loss of face-to-face contact with staff made safeguarding issues difficult to spot. Although calls to help lines such as Childline increased during the pandemic, such systems are not accessible to many disabled children.

I think the biggest concern for me as a practitioner has been the building impact of neglectful homes. That you, you know, we see for neglect that like cumulative effect and if you've got a window where you haven't seen the incremental changes, you're then presented with something that is at a point that it's unacceptable. So, we haven't been able to step in and intervene in a preventative way. We're then dealing with the protection and safeguarding matter. A1S_010

Impacts of Service Change on Parent Carer Health and Wellbeing

Reductions in services meant that parent carers were forced to take on the role of nurse, therapist, teacher, and counsellor as well as parent to their children 24/7 with no respite, whilst also juggling the demands of educating other children, caring for other family members, work and running the household.

10:30, we'd then try going to lessons. I'd try and do 3 hours and hours worked from 7:30 to 10:30. 10:30, we'd then try and teach, you know. Do his lessons feed him, do his medicines and do any online activity, I think we had online physio and PE so it's massage and all of that, which is what they do, you know, that's how they run it at school and then, you know try and do a little bit work in the evening and then we'd clean, we'd clean for two hours, we would steam everything and we did this. A2P_001

Usual physical and emotional support from friends or family wasn't available during lockdown or when shielding and as time went on social contacts were difficult to maintain online. Many parent

carers felt ill-equipped to deal with their child's level of need alone. They were seriously concerned about their child's worsening symptoms and the impact service reductions would have on their long term physical and mental health and educational outcomes. Parent carers also worried about the consequences if their child caught COVID, believing that treatment would not be offered and leading some to shield further. The unrelenting nature of lockdown and restrictions took a toll on parent carers' physical and mental health that were still being felt at the end of 2021.

I felt lonely and isolated and completely on my own. Trying to educate my son, who struggled to be educated. And trying to put this in the right possible way as well. Every day was a struggle. Just to be at home and it's a safe space, but it was just such a struggle. A3P_013

I remember it being to the point where, you know, I don't know if I can do this anymore. A5P_002

Learning from COVID-19 in Resetting Services to Disabled Children

It is clear that the impacts of services changes during the COVID-19 pandemic have been severe and long lasting for disabled children and their families. Even though all restrictions were lifted by July 2021, services are still dealing with unprecedented levels of demand arising from children who were already known who conditions have worsened and new children are referred with conditions that could have been treated by universal or targeted services but now require specialist intervention. As we reset services and help disabled children and their families we are recommending

- Adopt an Every Contact Counts approach to ensure opportunities to address issues efficiently
- Continue to offer telehealth appointments (including phone appointments) to deal with known conditions that can be described by parent carers and/or seen by practitioners, to save time for both families and practitioners
- Ask children and their parent carers about the impacts of the pandemic on children's health and wellbeing
- Prioritise assessment and diagnosis
- Ask parents about their health and wellbeing – signpost to psychological support and parent carer focussed health promotion programmes

In future emergencies the needs of disabled children must be considered. It is vital that wherever possible

- The ability to share information about individuals across sectors and services where necessary is instigated immediately
- Schools are kept open
- Health services continue in schools e.g. nursing and allied health
- Face-to-face appointments are available for prioritised conditions that place children at risk of severe morbidity or death
- Assessment and diagnosis is prioritised over continuing care
- An interdisciplinary, holistic approach to disabled children's care is adopted for maximum impact on their health, development and wellbeing

Conclusion

Reductions in services for disabled children and their families during the COVID-19 pandemic had serious, deleterious and lasting consequences for their health and wellbeing. We are now facing an unprecedented level of need, requiring integrated working across health, education and social care services to address children's multidimensional but inter-connected needs. New ways of working, including telehealth and increased interdisciplinarity, that enabled service delivery in COVID may help us develop models of care that can increase efficiency and reduce inequalities.

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