

## SCOPING REVIEW

# Impacts of health care service changes implemented due to COVID-19 on children and young people with long-term disability: A mapping review

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## Abstract

**Aim:** To identify the research on childhood disability service adaptations and their impact on children and young people with long-term disability during the COVID-19 pandemic.

**Method:** A mapping review was undertaken. We searched the World Health Organization Global COVID-19 database using the search terms 'children', 'chronic/disabling conditions', and 'services/therapies'. Eligible papers reported service changes for children (0–19 years) with long-term disability in any geographical or clinical setting between 1st January 2020 and 26th January 2022. Papers were charted across the effective practice and organization of care taxonomy of health system interventions and were narratively synthesized; an interactive map was produced.

**Results:** Reduction of face-to-face care and usual provision had a huge impact on children and families. Adoption of telehealth provided continuity for the care and management of some conditions. There was limited evidence of changes to mental health services, transitions of care, social care, or child-reported satisfaction or acceptability of service changes.

**Interpretation:** The long-term impacts of service change during the pandemic need full evaluation. However, widespread disruption seems to have had a profound impact on child and carer health and well-being. Service recovery needs to be specific to the individual needs of children with a disability and their families. This should be done through coproduction to ensure that service changes meet needs and are accessible and equitable.

In response to COVID-19, many countries applied measures and restrictions to limit virus spread, including 'lockdowns'. In the UK, these measures included social distancing, self-isolation, work-from-home mandates, and closure of some educational institutions.<sup>1</sup> Health care provision changed rapidly. Services deemed to be providing 'non-urgent care' suspended in-person appointments at home and in hospital and

community settings,<sup>2,3</sup> and many implemented telehealth (i.e. remote health care provision using telecommunication technology such as telephone, e-mail, and videoconferencing) to maintain contact with service users.

Service disruption adversely impacted children with disability and their families,<sup>4,5</sup> whose health, social care, education, and social support networks were all affected.

**Abbreviations:** AHP, allied health professional; ASD, autism spectrum disorder.

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Early in the pandemic, international surveys and interviews with families of children with a disability suggested that COVID-19 lockdowns were leading to an increase in children's needs, delays in assessments and diagnosis, and a deterioration in the mental health and well-being of parent carers and young people.<sup>6,7</sup> The nature and extent of restrictions and changes to multidisciplinary and multi-agency health care services and their effects, both negative and positive, is yet to be comprehensively evaluated.

This review aimed to identify research on childhood disability service adaptations and their impacts, and to map this evidence across health, education, and social care/welfare support to show the breadth, nature, and extent of evidence and detect gaps in our understanding.

## METHOD

The comprehensive mapping review protocol was published in full (<https://osf.io/4h29a/>) and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklists and elaboration because this extension also applies to evidence maps that share methodological similarities with scoping reviews.

### Population

Our population consisted of children and young people aged 0 to 19 years with confirmed or suspected long-term disability, their families, and professionals working with children with long-term disability. Long-term disability refers to a group of congenital or acquired long-term conditions that create functional limitations. These include neurodisability conditions attributed to impairment of the brain and/or neuromuscular system and congenital anomalies and genetic conditions affecting body structures and function.<sup>8</sup> Examples of conditions included are autism, cerebral palsy (CP), epilepsy, and Down syndrome. In a deviation from the protocol, studies were included if at least 90% of individuals in the sample were 19 years of age or younger to prevent the exclusion of papers that included a small adult sample alongside our population of interest.

### Concepts

Change to standard care or service delivery that occurred due to the COVID-19 pandemic was evaluated. This included service use (e.g. changes in the number of service contacts, planned and unplanned), changes in health and well-being outcomes associated with changes to service delivery, and experiences (attitudes, satisfaction, knowledge) of children, their parent carers, health care professionals, and family members during changed implementation.

### What this paper adds

- The biggest change was a reduction in in-person appointments and usual care.
- Telehealth for consultations and continued care was broadly feasible in medically led services.
- Telehealth was reported as less feasible for allied health-led care.
- School closures significantly impacted on young people's access to services, wider support, and routine.
- Widespread service disruption profoundly impacted the health and well-being of children, families, and carers.

### Context

All settings (e.g. school, home, hospital, social care, charity) within which changes to care and/or services occurred were considered; there was no geographical restriction.

### Study design(s)

All study designs were considered.

### Exclusion criteria

Studies reporting changes to any health service for the general population, which did not focus specifically on childhood disability or present their data separately, were excluded. Any study evaluating change to standard care or service delivery that were not due to the COVID-19 pandemic were ineligible. Interventions not directly implicated with service changes were excluded. Non-empirical studies, such as editorials and commentaries, were not eligible.

### Search strategy

The search strategy was developed with an information specialist. We searched the World Health Organization Global COVID-19 database, which collates published and preprint research from a range of sources and is updated regularly (Appendix S1); this included the most relevant range of sources for this topic (including social care, social sciences, and educational literature, as well as medical literature). This database was searched through a Web-based platform (<https://search.bvsalud.org/global-literature-on-novel-coronavirus-2019-ncov/>).

The main search terms of the search were children AND chronic/disabling conditions AND services/therapies (see Appendix S2 for the full search terms used). The search

terms included common neurodisability conditions that required multidisciplinary input; however, 'disability' was also included as a superordinate term to capture other long-term disabilities. The World Health Organization COVID-19 database permits searching with Medical Subject Headings and text word searches in the title, abstract, and subject terms of each record. To use Medical Subject Headings in this interface, tree numbers had to be used; thus, the search was initially developed in Ovid MEDLINE then translated to the World Health Organization COVID-19 database. The searches (starting from 1st January 2020) were run on 27th October 2021; 7532 results were retrieved in total, exported to the EndNote X9 reference management software (Clarivate, London, UK), and duplicates were removed; 7376 unique records remained. A second search was run on the 26th January 2022. An additional 1424 unique records were retrieved.

## Screening

Title and abstract screening was completed independently by two reviewers (from HM, HD, RPWK, CM) in Rayyan (<https://www.rayyan.ai/>), an online tool to aid screening in reviews.<sup>9</sup> Subsequently, the full texts of potentially relevant studies were sought and screened independently by two reviewers (HM, HD, RPWK, CM). Google Translate was used to translate studies published in a language other than English when necessary.

## Data extraction and charting

A single reviewer (HM, HD, CM) extracted all relevant data from the included full-text records using piloted coding tools within the EPPI-Reviewer 4.0 software (by EPPI-Centre, Social Science Research Unit, the Institute of Education, the University of London, London, UK).<sup>10</sup> Extracted data included: study design and methodology; geographical location(s); sample and participants; description of the change in service during COVID-19; outcomes measured and reported (e.g. cost of service change, service use/access, health and well-being outcomes, and experiences of service change); and descriptions of the impacts of the changes or themes identified. Ten percent of the papers were checked for accuracy and completeness by a second reviewer. Differences between reviewers were resolved by consensus before continuing with the remaining data extraction. The evidence was charted across sections of the effective practice and organization of care taxonomy of health system interventions to produce an interactive map providing an overview of the included research.<sup>11</sup> A narrative synthesis summarizes the data.

## Identification of research gaps through consultation

Four family advisory groups were set up through open, flexible recruitment.<sup>12</sup> Two groups consisted of parent carers

( $n = 11$ ) and two of young people ( $n = 8$ ). Parent carer groups were run online using Zoom, while the young people groups were held in person. Indicative research gaps identified by the research team were presented to the groups in one-off interactive events. Advice was sought on the importance of topics identified as gaps, which gaps were most important to address, and the knowledge or understanding required in those areas.

The advisory groups also identified additional gaps or areas of service change during the pandemic not identified through the review. Advisory groups were involved at a contributing level with their opinions used to shape and form the synthesis presented.<sup>12</sup>

## RESULTS

A total of 8800 records were screened at the title and abstract stage and 470 full texts were assessed for eligibility. Of these, 119 were included in the review (Figure S1). The most common conditions were epilepsy, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), and intellectual disability (Table 1). Table 2 provides further details about the characteristics of the papers and samples reporting on each condition. Most studies reported findings from hospital settings ( $n = 63$ ) or community care settings ( $n = 39$ ). Most papers reported parent carer-reported outcomes, while only five papers provided children and young people's self-reported outcomes. Most papers reported on data collected in the early stages of the pandemic from January 2020 to July 2020 ( $n = 87$ ), while 30 papers included data collected up to December 2020 and 11 included data collected in later periods of the pandemic (January to May 2021).

Forty-three papers reported cross-sectional survey findings about the experiences of families and professionals during the COVID-19 pandemic and a further eight papers reported mixed-methods findings. Ten papers were descriptive studies of telehealth programmes implemented during COVID-19 and 27 studies looked at the feasibility, acceptability, and/or effectiveness of telehealth using quantitative methods ( $n = 22$ ), mixed methods ( $n = 6$ ), and retrospective chart review ( $n = 3$ ) approaches. There were eight qualitative studies, eight papers reporting case studies, four review papers, and two studies comparing non-concurrent cohorts.

## Service change outcomes

The interactive map provides a visual overview of the research and gaps (<https://bit.ly/3PEzj1>). The most common service change reported on in the research was transition from in-person appointments to telehealth, followed by changes in the frequency of consultations, changes in in-person appointments, and increases in parent carer management (Table 3). Initial virus containment measures resulted in sudden and extensive suspension of services across all countries, service types, and settings. Rapid uptake in

**TABLE 1** Summary of diagnosis group by study design with a description of sample sizes

	National survey <sup>a</sup>		Clinical group/setting <sup>a</sup>		Medical records review <sup>a</sup>		Qualitative <sup>a</sup>		Case study <sup>a</sup>		Total	
	Papers	<i>n</i>	Papers	<i>n</i>	Papers	<i>n</i>	Papers	<i>n</i>	Papers	<i>n</i>	Papers	<i>n</i>
Developmental disorders <sup>b</sup>	16	3818	19	4289	4	443 167	6	185	1	14	46	451 473
ASD	3	590	6	855	2	170	0	0	3	8	14	1623
Epilepsy	7	11 346	4	223	1	204	1	8	0	0	13	11 781
ADHD/ASD/intellectual disability	3	387	3	388	2	359	1	117	1	0	10	1251
ADHD	0	0	1	40	1	190	1	61	0	0	3	291
Cerebral palsy	0	0	6	531	1	100	0	0	0	0	7	631
Genetic condition/syndrome	1	125	1	216	0	0	0	0	1	1	3	342
Physical disability/learning disability	0	0	4	227	1	18	0	0	1	3	6	248
Congenital	1	301	1	45	0	0	0	0	0	0	2	346
High-risk infant follow-up	1	144	2	108	0	0	0	0	0	0	3	252
Vision/hearing impairment	1	533	2	1062	0	0	0	0	1	1	4	1596
Neuromuscular disease	1	23	0	0	0	0	0	0	0	0	1	23
Fragile X syndrome	1	67	0	0	0	0	0	0	0	0	1	67
Intellectual disability	1	48	0	0	0	0	0	0	0	0	1	48
<b>Total</b>	36	17 382	49	7984	12	444 208	9	371	8	27	114 <sup>c</sup>	–

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder.

<sup>a</sup>National survey refers to online surveys sent out to groups via social media or groups; clinical group/setting refers to studies that took place within a specific clinical setting (e.g. a hospital or a hospital department); medical records review refers to studies reporting descriptions of data retrieved from medical records; qualitative studies include papers reporting on interviews and analysis of social media group content; case studies refer to papers describing the experience of one or more specific cases.

<sup>b</sup>Developmental disorders refers to studies that included a sample of children with neurodevelopmental needs, covering all other diagnoses listed in the table, but where results were not disaggregated by specific diagnosis.

<sup>c</sup>The total is missing five records that were literature reviews ( $n = 4$ ) or a quality improvement study ( $n = 1$ ).

**TABLE 2** Summary of information about the 119 papers identified by the review

Filter	Total number of papers coded (n = 119)	Percentage of total papers (n = 119)
<b>Setting</b>		
Hospital	64	53.8
Community	39	32.8
Educational setting	18	15.1
Social care	11	9.2
Charity/third sector	3	2.5
Undefined	12	10.1
<b>Age group of children and young people</b>		
Preschool (0–5 years)	61	51.3
School-age (5–16 years)	85	71.4
Postschool (16+ years)	35	29.4
Not reported	4	3.4
<b>Group reporting</b>		
Parent carers	76	63.9
Professionals	50	42.0
Children and young people	5	4.2
<b>Sample size</b>		
1–10	10	8.4
11–30	12	10.1
31–100	33	27.7
101–500	47	39.5
501–1000	5	4.2
>1000	5	4.2
Not applicable	7	5.9
<b>Geographical location</b>		
USA	34	28.6
Italy	18	15.1
India	11	9.2
UK	9	7.6
Turkey	6	5.0
Canada	6	5.0
International	5	4.2
France	5	4.2
Spain	3	2.5
Germany	3	2.5
China	2	1.7
Israel	2	1.7
Australia	2	1.7
Philippines	2	1.7
Saudi Arabia	2	1.7
Argentina	1	0.8
Brazil	1	0.8

(Continues)

**TABLE 2** (Continued)

Filter	Total number of papers coded (n = 119)	Percentage of total papers (n = 119)
Denmark	1	0.8
Hong Kong	1	0.8
Iran	1	0.8
Ireland	1	0.8
Norway	1	0.8
Poland	1	0.8
Romania	1	0.8
Jordan	1	0.8
Iceland	1	0.8
Tunisia	1	0.8
Singapore	1	0.8

Records discuss multiple conditions/groups/settings; thus, single records are not coded to conditions and outcomes in a mutually exclusive manner.

telehealth enabled some continuity of care. There was increased use of videoconferencing in some settings across medical care, allied health professions, and some educational settings. Some services ceased to be provided, were not replaced by telehealth initially, and did not return until face-to-face services resumed. Alongside this, there was an increased reliance on parent carer management, with parent carers trying to maintain therapies and monitoring their child's health at home.

The narrative synthesis below gives a detailed outline of the findings reported in the identified papers. This narrative separates the findings into three categories: (1) medically led services, where care is led by doctors and delivered by doctors, nurses, and other health professionals; (2) allied health-led services, providing rehabilitation, health, and developmental management including therapy, psychology, and nutrition; and (3) educational settings, social care, and voluntary sector settings, related to services delivered to support social and educational outcomes.

## Medically led services

### Frequency of consultations

Twenty-three papers reported the disruption to service frequency of hospital and medical service delivery. Reinstatement of service delivery through telehealth prioritized children and young people who required medical monitoring and intervention. Two studies reported that emergency attendances reduced markedly during the pandemic.<sup>13,14</sup> Two studies comparing emergency and primary mental health appointments from before and after lockdown at the start of the pandemic described a decline in the number of consultations during the initial period, with consultation volumes returning to prepandemic levels by June 2020.<sup>15,16</sup>

**TABLE 3** Service change outcomes reported

Outcomes	Total number of papers coded	Percentage of total papers (n = 119)
Telehealth	91	76.5
Videoconferencing only	38	31.9
Telephone only	2	1.7
Combination of telephone and videoconferencing	27	22.7
Mobile app	2	1.7
Telemonitoring (remote access to equipment)	2	1.7
Not reported	20	16.8
Who delivers care and how it is managed		
Frequency of consultations	63	52.9
Self-management (shifting or promoting the responsibility for health care to the patient and/or their family)	25	21.0
Role expansion (expanding tasks undertaken by a cadre of health workers)	2	1.7
Where care is delivered		
In person	27	22.7
Outreach work	5	4.2
Site of service	1	0.8
How and when		
Triage	4	3.4
Coordination of different care providers	0	0
Queuing strategy	2	1.7
Group vs individual	0	0
Coordination of care and management of care process		
Integration	4	3.4
Shared care	1	0.8
Transition	0	0
Health outcome		
Management of condition	40	33.6
Child physical health outcomes	22	18.5
Child behaviour outcomes	20	16.8
Child mental health outcomes	6	5.0
Child well-being outcomes	8	6.7
Diagnostic assessments	10	8.4

**TABLE 3** (Continued)

Outcomes	Total number of papers coded	Percentage of total papers (n = 119)
Parent well-being	18	15.1
Parent mental health	5	4.2
Experiential outcomes		
Satisfaction	53	44.5
Feasibility	20	16.8
Equitability	9	7.6

Records discuss multiple outcomes; as such, single records are not coded to conditions and outcomes in a mutually exclusive manner.

Half of medical appointments for children and young people with epilepsy scheduled before lockdown were postponed and two-thirds of children and young people had a specialist appointment cancelled.<sup>13,17,18</sup> In a study across 49 countries, nearly all clinicians reported reduced access to an electroencephalogram (EEG), that epilepsy surgery was on hold for one-third of children and young people, and that they could only initiate diet therapies (for example, the ketogenic diet) for urgent cases.<sup>19</sup> Two-thirds described a decreased admission rate for new-onset infantile spasms. Clinicians reported that epilepsy surgery evaluations and epilepsy surgeries were mostly limited to urgent and life-threatening cases.<sup>19</sup> The study recommended that the risk–benefit analysis of delayed surgeries and diet initiations should be carefully considered. There were mixed reports on changes in seizure frequency for children and young people with epilepsy indicating that this was a result of service disruption and the wider difficulties experienced during the pandemic.<sup>13</sup> For example, one study reported that an increase in seizures was associated with parent carer reports of difficulties in giving timely medication due to loss of daily routine.<sup>20</sup> Broader impacts such as changes to routine were also reported to result in behavioural deterioration for children and young people with epilepsy.<sup>18,21</sup>

Some postponement of medical appointments was reported in the treatment of children and young people with CP and delays were reported in administering botulinum neurotoxin A injections, although medical appointments were more stable than access to therapies.<sup>22,23</sup> One study reported that these delays resulted in an almost six-fold increase in pain complaints and worsening of spasticity.<sup>22</sup>

### Continuation of in-person appointments

In-person appointments remained highest in medically led compared to allied health professional (AHP) services, with up to 75% of studies reporting maintaining some in-person hospital appointments. The establishment of ‘COVID-free’ hospitals<sup>24</sup> and separate clinic hours for infection- and non-infection-related consultations<sup>25</sup> allowed the continuation

of routine appointments in some settings. Elsewhere, it was reported that in-person appointments or inpatient admissions were only maintained for urgent or non-deferrable cases.<sup>19,26,27</sup>

## Telehealth

Thirty-one papers reported on telehealth for medically led care. Fourteen of these described children and young people accessing continued care for, or being assessed for, epilepsy via telehealth during the pandemic. While one study reported continued difficulties in accessing health care for epilepsy treatment, describing a scarcity in telehealth,<sup>21</sup> the implementation of telehealth largely enabled the reinstatement of monitoring and treatment of children with epilepsy.<sup>19,28</sup> Telehealth was used for planned clinic appointments with a consultant, medical follow-ups, and to get prescriptions or medications amended. Telehealth was also used for joint appointments with a neurologist and dietician to initiate ketogenic dietary therapy.<sup>19,29,30</sup> Telephone consultations were supplemented with the family sending images or videos. Three papers described using telehealth to diagnose new referrals with suspected epilepsy.<sup>19,31,32</sup> For new referrals, it was recommended they came in for an EEG as soon as in-person visits to hospital for non-urgent care were allowed, or families attended a hospital for an EEG, but follow-up appointments were done remotely. An international survey reported that 70.1% of surveyed clinicians had moved outpatient appointments to telehealth but maintained in-person appointments for urgent cases.<sup>19</sup>

Two papers reported on the use of telehealth for the medical care of children and young people with CP.<sup>7,33</sup> The frequency of medical follow-up via telehealth ranged from 18% to 50% of samples. Online consultations were used for appointments with paediatricians, orthopaedic surgeons, and neurologists. One study reported that 48.5% of their sample were advised about surgery before the pandemic; 28.7% could undergo surgery during the pandemic.<sup>33</sup>

The remaining papers described the use of, or frequency of, telehealth appointments for consultations with medical professionals for children with neuromuscular disease,<sup>34</sup> ADHD,<sup>35,36</sup> and high-risk infant follow-up.<sup>37</sup> One paper described the use of a smartphone social media app to allow parent carers of children with congenital heart disease to access relevant information and contact a heart surgeon during the pandemic.<sup>38</sup> They reported that the app was useful in monitoring a child's condition and managing parent carer anxiety.

Three papers reported on medical services for children with neurodevelopmental disabilities.<sup>17,39,40</sup> A study of adolescents with special educational needs used linked education, health, and social care data, which identified that a greater proportion of adolescents with special educational needs had outpatient appointments offered to them via telehealth compared to their peers.<sup>39</sup> One survey reported that 30.9% of follow-up appointments for children with

neurodisability with a paediatrician were carried out via telehealth.<sup>17</sup>

Two papers described successful remote telemonitoring of children and young people's ventilation and continuous EEG, reducing the need for children and young people to travel into hospital or be admitted for monitoring.<sup>41,42</sup> One study reported that most high-risk infant follow-up clinics moved to telehealth.<sup>37</sup> Telehealth was suggested to improve outreach and engagement with families, especially those that lived further away from the clinic; however, many medical professionals reported it was difficult to perform adequate medical and developmental assessments in this clinical group.

Several studies collected information on satisfaction with telehealth appointments, finding that both parent carers and health care professionals had confidence in the remote contact and the clinical evaluations undertaken via telehealth.<sup>18,30,43</sup> Parent carers reported finding telehealth appointments helpful and effective and were supportive of video consultations continuing beyond the pandemic,<sup>18,32,43,44</sup> seeing benefits of saving time and travel to the hospital and waiting rooms and avoiding the challenges related to bringing their child to an outpatient appointment.<sup>29,37,44,45</sup>

Some of the negative evaluations of telehealth from both parent carers and health care professionals was the absence of the physical examination<sup>32,37,44</sup> (e.g. measures of weight and height, evaluation of motor development) and some found it less personal and hard to build rapport.<sup>46,47</sup> In general, access to and availability of technology was a challenge in being able to deliver telehealth. Where reported, telehealth was seen as a feasible method of continuing monitoring and care of children and young people during the pandemic in medical care settings.<sup>28,42,48</sup>

## Parent carer management

Five papers reported on parent carers taking more responsibility for managing their child's medical care. Ketogenic diet therapies were managed through remote delivery via apps and by telephone. Parents reported very high levels of satisfaction with online support.<sup>30,49</sup> One paper described offering an outreach advice service for congenital heart diseases.<sup>38</sup> Adherence to self-management was sustained or increased when contact with health professionals could be maintained.<sup>49</sup> Studies indicated efficiencies where practitioners were already accustomed to using remote support and telehealth systems before the pandemic.<sup>30</sup>

## Services led by allied health professionals

### Frequency of consultations

Forty-seven papers refer to frequency of consultations with AHPs. Severe disruption to AHP interventions was evident, with many parents reporting interruption to occupational

therapy, speech and language therapy, physiotherapy, and psychological therapy; some reported no therapy delivery at all for children and young people with a long-term disability. One large study of children with ASD reported that over three-quarters experienced moderate-to-severe disruptions in services delivered at schools and professional clinics.<sup>50</sup> Children and young people with neurological disorders, primarily epilepsy and CP, reported that approximately half of their allied health appointments stopped or were disrupted, particularly physiotherapy and occupational therapy.<sup>7,13,17,18,22,33</sup> This disruption included access to equipment services and specialist services such as orthotics, impacting on children and young people's health and family well-being.<sup>33,51</sup>

Many papers reported negative health outcomes in children where AHP services were disrupted or stopped. In one study, over half of participants reported 'some' or 'significant' decline in their child's functioning in communication skills, social skills, and behaviour due to changes in their child's access to opportunities, settings, or equipment, with greater impact for children with multiple diagnoses.<sup>52</sup> Children with CP were reported to show deterioration in their physical condition with reports of over half showing increased spasticity, reduced range of joint motion, and ambulatory change.<sup>22,53</sup> Reasons for deterioration included decreased duration of orthosis and assistive device use, levels of therapy, and indoor and outdoor activity participation.<sup>22,23,42,53</sup>

Concern about child growth and development without specialist rehabilitation programmes was linked with the mental health of caregivers; parents described increased anxiety and stress. A group of health care professionals in the UK indicated that when services closed, parents of younger children were worried about missed 'early developmental opportunities' due to lack of targeted therapeutic support.<sup>51</sup> This study also reported that many parents of teenagers confirmed that therapy input was no different during lockdown because they did not usually have access to therapy. The inequity of access to existing services was of significant concern to parents and clinicians.

## Telehealth

Forty-nine papers described the frequency of use or delivery of telehealth appointments with AHPs. Most papers reported on multiple allied health services or 'therapy' in general ( $n = 28$ ). The remaining papers were focused on behaviour programmes (e.g. behaviour counselling, applied behavioural analysis therapy;  $n = 9$ ),<sup>54-62</sup> speech and language therapy ( $n = 4$ ),<sup>63-66</sup> physiotherapy ( $n = 3$ ),<sup>53,67,68</sup> mental health support ( $n = 2$ ),<sup>69,70</sup> auditory-verbal therapy for children and young people with a hearing impairment ( $n = 1$ ),<sup>71</sup> rehabilitative therapy for children and young people with vision impairment ( $n = 1$ ),<sup>72</sup> and early intervention coaching ( $n = 1$ ).<sup>73</sup>

The percentages of families reporting attending a telehealth appointment with an AHP tended to be lower (less

than 50% of study samples) than those reported for medical care appointments (over 50% of study samples). This was either because telehealth was not available or families chose not to participate in or continue with telehealth appointments for allied health care.

Parent carer satisfaction with telehealth varied widely. Overall, satisfaction was lower for appointments with AHPs than described in medically led care. Higher parent carer satisfaction was associated with the child's enthusiasm to participate and greater flexibility of therapists to modify activities to the child's needs and ability to maintain the child's engagement in the session. Two papers compared parent carer and health professional satisfaction with telehealth; in both papers, parents reported greater satisfaction than health care professionals in terms of effectiveness, confidence, acceptability, and similarity to in-person appointments.<sup>72,74</sup> However, overall parent carers reported being less satisfied with telehealth services compared to usual in-person services and reported it as not being inherently the same as face-to-face therapy.

Telehealth delivered by AHPs more often required the presence of the child online alongside, or supported by, the parent carer compared to medical appointments, where consultations were often with parent carers only. Parent carer dissatisfaction with telehealth was reported to be due to the child's inadequate attention span, sitting tolerance, inability to understand instructions, and poorer interaction with the therapist. However, for others, the use of telehealth was reported to have increased parent carer collaboration with the AHPs because the parent carer needed to have more involvement and training in their child's therapy activities during lockdown. As with most telehealth services, technical issues emerged, such as lack of connectivity and difficulties in listening or watching the professional during the visit.

Where tailored allied telehealth interventions were established during the pandemic, parent carers reported more positive outcomes in their child's development, particularly for younger children.<sup>48,68,75</sup> These tailored programmes and other outreach programmes delivered online allowed parent carers to access therapy input and carry out therapies in the home environment but appeared to be more relevant to continuing skills rather than improving outcomes.<sup>49,53</sup> A virtual reality rehabilitation system home kit was found to be feasible for providing rehabilitation for an adolescent with a motor disorder; however, it required sufficient space in the home and for the family to understand how to use the system.<sup>67</sup>

Three papers reporting on telehealth for behavioural interventions described development of specific services to support parent carers and children and young people during the pandemic.<sup>56,59,76</sup> Each programme was delivered using telehealth specifically to provide support for children and young people with maladaptive behaviours, aggression, and outbursts that were directly related to the pandemic and home confinement. The services provided advice to families and direct work with the children and young people via behavioural therapists. Parent carers indicated they would be

willing to engage in telehealth support for behaviours that challenged if it was available to them.<sup>57</sup> However, a large majority of parent carers reported that behavioural telehealth had not been offered to them in any form during lockdown.

Very few studies have been able to evaluate the direct impacts of moving to telehealth on children and young people's health outcomes. Social and language outcomes were reported as deteriorating, and autistic restrictive, repetitive, and stereotyped behaviours were reported as increasing.<sup>77-79</sup> Clear correlation with deterioration in behaviour and change in services was not established in most studies; multiple factors such as loss of medical and therapeutic services, changes to routine, and other restrictions were cited as influencing factors. However, one study reporting on a large survey of caregivers of children and young people with ASD concluded that children who were younger, from low-income families, and with greater impairment severity (more severe repetitive behaviours, language, cognitive, function, and motor impairments) were more negatively impacted by the pandemic through service disruptions.<sup>50</sup>

Concerns about child development without proper service support or access to specialist therapeutic services emerged as the highest source of psychological distress for families of children and young people with ASD.<sup>50,80</sup> One study noted that parents who reported regression in their child's skills due to service loss, felt a helplessness when trying to provide intervention to their children with ASD and learning disability.<sup>81</sup> The study recommended involving parents of children with disabilities in therapy so that they gained the skills to maintain therapy in a future crisis.

## Parent carer management

Fourteen papers described a shift to therapies or interventions being delivered by parents. Parent carers of children with physical disabilities reported that they performed between 62% and 83% of therapies for children and young people, covering physiotherapy, occupational therapy, speech and language therapy, psychomotor therapy, and orthoptist sessions.<sup>7</sup> Parent carer management of CP resulted in differing levels of programme compliance. Parents reported trying to adhere to therapeutic intervention programmes sustaining moderate levels of therapeutic intervention, while others reported that they were unable to continue therapies at home due to lack of knowledge and lack of access to equipment.<sup>33,51,82</sup>

Three papers described setting up outreach services through online resources for families of children with behavioural support needs to access, during the pandemic, advice on therapies and advice specifically related to COVID-19.<sup>62,78,83</sup> A development and behavioural paediatric service also described identifying vulnerable families of children and young people with ASD and initiating an outreach programme with targeted phone calls to support these families while services were closed or only able to offer limited in-person appointments.<sup>62</sup> Where behavioural

interventions were established before lockdown, parent carers were more able to continue these programmes.

Parents reported difficulties with increased emotional load, anxiety, stress, and depressive symptoms. Parent carers expressed a need for help and assistance from people, psychological support, and/or recommendations to support their child's learning, and manage their child's condition.<sup>7,84</sup>

## Education, social care/welfare, and third sector organizations

Less evidence was found on changes to education, social care/welfare settings, and third sector organizations than medical and allied health care (Table 2).

### Frequency of consultations

Parent carers described the difficulties in managing their child's health, therapeutic, and specialist educational needs when services were disrupted, reduced, or stopped.<sup>85</sup> Loss of respite services and school closure left many families struggling to cope with children's emotions and behaviours.<sup>51,86,87</sup> Papers reported increased stress, anxiety, and depressive symptoms in parents trying to deliver home care and manage the additional challenges of home working and home schooling without respite services.<sup>83,88,89</sup> School closures resulted in significant disruption, with reduced or no attendance for many. Services working through schools were substantially disrupted. The vast majority of children and young people lost specialist therapeutic services delivered through school and 44% of parent carers reported a lack of equity of access to school support and online learning because it was not adapted to the needs of children and young people with disabilities.<sup>90,91</sup>

Parent carers reported closure or severely reduced access to respite services which had been in place before lockdown,<sup>57,79,92</sup> which along with closures of outside activities or school impacted their own mental health and coping strategies.<sup>51</sup> An online survey of children with special educational needs reported poorer mental health than typically developing children and increases in distressed behaviours alongside increases in maltreatment, including physical assault and aggression compared to pre-COVID-19.<sup>93</sup>

Several papers described the parent carer strain of managing their children and young people's behavioural needs with loss or disruption to resources such as respite care, school, social care, and their support networks. Parent carers reported the reappearance of behaviours that challenged what, previously, had been well managed.<sup>94</sup> A survey of parent carers found that, compared to before the pandemic, behavioural problems were reported as being more intense and more frequent in a substantial proportion of individuals with ASD.<sup>77</sup> Parents felt unable to meet their children and young people's needs or access support and held worries over the long-term impact on their child.<sup>6,94</sup> Nevertheless, some

families cited the reduced demands on their child as having a positive impact on their child's well-being, often describing reduced anxiety.<sup>6,95</sup> Parent carers also reported that children's communication skills had improved.<sup>6,53</sup>

## Telehealth and parent carer management

The number of papers describing or evaluating telehealth in education and social care/welfare settings was much lower compared to medical care and AHP services. Schools responded by developing outreach support to meet family needs beyond core educational delivery. Two studies reported special education teachers' provision of support to families of children with special educational needs.<sup>83,89</sup> Emotional support was seen as central to enabling families to manage behaviours that challenge. Teachers provided online resources, coaching, and activities to the families to address their specific needs.<sup>83,89</sup> One paper reported the response of an ASD day care service to support families, where shared care had been impacted by in-person closure.<sup>75</sup> The service provided group and individual online training and support daily; parent carers were given guidance on structured teaching, behavioural approaches, and environmental adaptations to accommodate the child's communication and sensory needs.

Parents widely reported receiving little or no support with children's specialized learning and behavioural needs.<sup>89,96</sup> Teachers reported barriers to implementing interventions for behaviours that challenge in the home because it was difficult for parents to understand the function of their child's challenging behaviour, identifying the need for more integrated working between school and family.<sup>83</sup> UK research indicated that access to support for families strongly impacted their overall experience, yet many parent carers reported that they needed to reach out to access support rather than a system-driven approach to provide support.<sup>94</sup>

## DISCUSSION

This mapping review of research published between January 2020 and January 2022 indicates that there was a sudden and extensive suspension of services, including those supporting children and young people with disability. This led to a shift to, and increased use of, telehealth, particularly videoconferencing, across services for children with disability. The use of telehealth for consultations and continued care was mostly described as successful in medically led services, with parent carers and professionals reporting high satisfaction and engagement with telehealth appointments. The use of telehealth for allied health provision was lower than in medical care settings and faced greater challenges in being able to deliver an equivalent level of service to in-person therapies. For many, telehealth was described as being beneficial in providing some level of continuity of care to children and young people while restrictions were

in place. While some parent carers and professionals saw a place for telehealth appointments in the future, postpandemic, both groups reported wanting to return to in-person appointments, highlighting that telehealth did not enable access to health care for all children and young people. In particular, some diagnostic assessments of new referrals did not work as well via telehealth and many described not reaching therapy goals through telehealth. We found limited research describing the changes made in education, social care, and voluntary sector settings, although changes were made.

A small proportion of papers reported on the specific impact of service disruption on health outcomes for children and young people. Parent carers and professionals reported that the impacts of stopping or interrupting care included: reduced access to medications for seizure control; declines in children's mobility; increases in pain; and declines in children's communication skills, social skills, and behaviour. There was some evidence that age, number of diagnoses, severity of condition, and living conditions were factors in how service disruption impacted on children and young people's outcomes. There were also the wider impacts of the societal measures implemented during the pandemic with stay-at-home measures, reduced play and social interaction opportunities, and access to support networks impacting on the outcomes for children and young people with long-term disabilities.

## Gaps in the evidence for service change

### Mental health support

Many papers reported on the impact of the pandemic on children and adolescents' mental health and changes in access to emergency mental health services during the pandemic.<sup>97-99</sup> However, most of these papers were excluded from this review due to not reporting data specific to children with long-term disabilities. Research should evaluate the mental health impacts of the pandemic on children and young people with long-term disabilities and how and whether mental health services can respond effectively to their specific needs, especially since generic interventions may be less accessible to young people with disabilities.

### Social care, welfare support, and short break services

A report in the UK on the impact of the COVID-19 pandemic on the education, health, and social care provision for children with special educational needs and disabilities highlighted the impact of the loss of short break services on children and young people, parent carers, and the wider family during the pandemic.<sup>100</sup> However, we found limited published peer-reviewed literature on successful models of adapting social care and welfare provision for children

and young people with disability. The international literature highlighted the detrimental impacts of loss of welfare and social support on family's mental health and well-being during the pandemic.<sup>79,92</sup> There is a need to identify models of working in these settings that worked well during the pandemic.

### Transitions during the pandemic

None of the papers identified in this review discussed how transitions from child to adult health services, and/or school transitions (starting and leaving school or changing schools), were managed during the pandemic, nor the effect of service changes, such as moving to telehealth or a drop in frequency of appointments on the management of transitions. Existing research already demonstrated how challenging transitions from child to adult health care services can be for disabled young people.<sup>101,102</sup>

### Child and young person self-reported outcomes

There is a relative paucity in the reporting of children and young people's own experiences of changes to services during the pandemic. Only five studies reported from this perspective, with two studies not differentiating the parent carer and children and young people perspectives in the results. While the views of parent carers and professional perspectives are essential, young people's own views are critical so that interventions are acceptable and fully address the challenges experienced by disabled young people. While several of the papers identified in this review reported both qualitative and quantitative impacts of the pandemic and service disruption, further work is needed to understand the impact on health outcomes for children and young people and parent carers.

### Children and young people awaiting diagnosis or newly diagnosed

Within the research identified, there was some discussion of how services approached new referrals, particularly in epilepsy services. The experience of receiving a diagnosis during the pandemic and how families were supported after the diagnosis is not elucidated. Likewise, the consequences of longer waiting times for assessment arising in the pandemic is yet to be explored.

The impact of the pandemic on infant and young children's development has been well documented.<sup>103–105</sup> Consequences could be exponentially greater for children with additional needs, especially if parents have little exposure to other infants. It is vital to understand the impact of delayed access to early years assessments to inform future services and plan for the potentially long-term health and developmental impacts in this population.

### School closures and access to therapies

There is little peer-reviewed evidence of the impact of school closures on access to services including AHP, behavioural support, and adapted and specialist curriculum/learning support delivery (which is frequently the vehicle for therapy delivery). However, this loss of the wider school services was reported by our young people advisory groups as highly significant. The advisors also referred to the less formal developmental opportunities accessed through schools such as social interaction and social skill development, preparing for adulthood and transition, and the importance of school as a source of routine. They suggested that the developmental and mental health implications of losing these services and networks will impact their health and well-being into the future.

### Inequality of access and impact

Our parent carer and young people's advisory groups raised in discussion the importance of acknowledging the existing inequalities in access to services and resources, in particular access to information technology and Internet resources to engage in telehealth. The reported increased use of telehealth in this review indicates the need to address digital poverty and equal access to technology and resources across services and conditions. This inequality in impact indicates a need for the identification of targeted 'catch up' and recovery for children and young people with disability. There is a pressing need to understand how services are recovering from the changes made and responding to increased waitlists and demands for services and support.

### Limitations

The studies included in our mapping review represent those identified using our predefined search terms, which focused on children and young people with neurodevelopmental types of long-term disabilities (as exemplars of conditions requiring multidisciplinary input) and service change. The review was focused on peer-reviewed published papers; however, there is a non-academic publication relating to service change for children and young people with disability that would have not met the criteria for inclusion in our review. The focus on the experiences and outcomes for children with long-term disability meant that many papers had to be excluded due to not segregating findings by the clinical groups of relevance for the review. Since we conducted a mapping review over a rapid time frame, we did not conduct formal quality assessment of studies.

It is possible that gaps identified in the changes to social care and welfare services and educational settings are reported more widely in grey literature rather than peer-reviewed journals. Most of the studies identified in this review reported on changes and outcomes from earlier periods

of the pandemic. The 27 new studies identified in our second search in January 2022 indicates how evidence in this area is growing. However, it is important to note that despite the increased number of published papers between October 2021 and January 2022, the types of research and outcomes reported did not change substantially.

## Conclusion

While all children and young people have felt the impact of COVID-19, the increased reliance on health, social care, and educational services for children and young people with long-term disabilities has resulted in a disproportionate impact on this population. The widespread withdrawal and disruption to many of these services has had a profound impact on the health and well-being of children and parent carers. In particular, the loss of access to educational settings and short breaks impacted parent carer health and well-being. Future planning for emergencies needs to involve families to understand what access to services and support is needed in times of emergency.

In response to the stopping of in-person provision of care, the adoption of telehealth increased across services and settings. While this change provided continuity of some care and some management of conditions, the adoption of telehealth did not enable access to health care for all children and young people and was especially challenging for allied health-led services. Further research and evaluation of telehealth is needed to understand what does and does not work in the provision of high-quality care to disabled children via telehealth in the recovery of services and for future emergency planning. This review exposes the minimal engagement of children and young people in research about 'reset' services that provide care and support to them indicating a need for their greater inclusion in service codesign and future research.

The longer-term impacts of the changes in services are still to be seen and evaluated fully. Service recovery needs to be differentiated to address the specific needs of children and young people with disability, which should be done through coproduction with families to ensure that changes are meeting needs and are accessible and equitable so that health disparities are not exacerbated. This mapping review is part of a broader methodology including qualitative interviews with professionals and parent carers in England and a Delphi study designed to provide substantive recommendations for services to disabled children in times of emergency (<https://fundingawards.nihr.ac.uk/award/NIHR202478>).

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## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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## SUPPORTING INFORMATION

The following additional material may be found online:

**Table S1:** List of excluded papers.

**Figure S1:** PRISMA flow diagram.

**Appendix S1:** Databases and Journals covered by WHO Covid database.

**Appendix S2:** Full search terms used.

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