

Communication in disasters to support families with children with medical complexity and special healthcare needs: A rapid scoping review

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During times of disaster or crisis, normal patterns of care can be disrupted, perhaps for quite a period of time, with potentially serious or deadly effect on children who depend upon regularly scheduled and uninterrupted access to the health care system. Particularly at risk are children with medical complexity (CMC), who have chronic medical conditions often with technology dependence (e.g., feeding tubes). These children represent about 1% of the pediatric population but require approximately 30% of pediatric health care resources, including hospital and community care (Cohen et al, 2012). For instance, in Canada, among this population 68% are reported to require at least one emergency department visit per year, and 36% are hospitalized at least once per year. The average number of hospitalizations for a CMC annually is 2.5, with an average hospital stay of 21 days (McKenzie et al, 2021).

The families of these children rely on teams of health care professionals, spanning the hospital and the community, to partner in their care. However, lack of clear, standardized and evidence-based processes for communication among families and healthcare teams during disaster-related disruptions can make it very challenging for families to maintain needed access to services and supports.

Given that relatively little is known about this topic, and there is pressing need due to the current COVID-19 pandemic to synthesize available evidence as a beginning guide for policy discussions, the authors here undertook a rapid scoping review approach to knowledge synthesis. Rapid reviews provide “actionable and relevant evidence in a timely and cost-effective manner” (Langlois et al, 2017, 3), and “scoping studies ... map rapidly the key concepts underpinning a research area and the main sources and types of evidence available” (Mayes et al, 2001, 194). Knowledge in a broad range of forms is expected to be relevant.

The focus of the research thus addressed such questions and topics as:

1. The presence of healthcare disaster preparedness plans for families of children with special care needs.
2. Procedures adopted during disasters (case reports, national or regional plans, news reports etc.).
3. Healthcare administrative planning pertaining to role of hospitals and other healthcare services during disaster -- what protocols are in place, how are these protocols initiated, and what is the role of different individuals?
4. Lines of communications between healthcare providers and the families of CMC, methods of maintain access to needed services, communication protocols and messaging and their efficacy during disasters, drawing upon reports, anecdotes, studies or media information pertaining to disasters and how were these addressed.
5. Reports from healthcare professionals, including doctors, nurses and social workers on coordinating disaster communications, and any experiences (reports, studies) therein.

Background: Key Concepts

Children with Medical Complexity

One of the challenges in this review is determining if different studies include comparable populations, and/or if the communication challenges are similar or different across settings and among specific groups of professionals or pediatric patients. The broadest term is perhaps CAFN, or Children with access and functional needs (e.g., as used in Chin et al, 2020), which “is now preferred to the term ‘special needs,’” (National Academies of Science [NAS], 2014, p70) as being more inclusive. Boon, Brown, Tsey et al (2011) note that children with disabilities, and children with special health care needs, are not necessarily synonymous terms (p232); presumably not all children with disabilities require substantial additional on-going medical care. It is more common to consider persons with disabilities as a sub-group within this larger population (See for instance: <https://www.mass.gov/info-details/emergency-preparedness-for-individuals-with-disabilities-and-access-and-functional>). Kailes and Lallor (2021) present the CMIST framework, which breaks functional need into five sub-categories: communication (C); maintaining health (M); independence (I); support, safety, and self-determination (S); and transportation (T).

Terms more specific to the health sector and in relatively common use here include CSHCN—Children with Special Health Care Needs - which is typical nomenclature in the United States, and CMC, or children with medical complexity.

CSHCN is formally defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (cited by Bagwell), and would include chronic conditions such as diabetes or asthma. US estimates are that this includes 15% of all children (Bagwell et al, 2016). CMC can be seen as a subset of CSHCN (Cohen et al, 2011; Gillen and Morris, 2019). The term is defined by Cohen et al as “children who are the most medically fragile and have the most intensive health care needs. ... and includ[ing] children who have a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, or patients with cancer/cancer survivors with ongoing disability in multiple areas” (2011). According to Cohen et al, “CMC are ... children with characteristic patterns of needs, chronic conditions, functional limitations, and health care use” (2011). In their systematic review, Hipper et al used the definition, “children with chronic, severe health conditions and major functional limitations” (2018, p179).

More expansive definitions of special needs children, such as the inclusion of those with intellectual or behavioural challenges, make the population more difficult to identify in advance (Kaziny, 2014). On the other hand, there are also papers which use more restrictive definitions limiting their scope to subsets of CMC, and so implications for supports and communication needs during disasters might not be generalizable to the larger group of CMC. Examples include Hoffman et al (2018) who use both CMC and the term VPP (vulnerable pediatric patient), defined as being those who are technology-dependent. In a 2009 paper, Uscher-Pines et al focus upon the needs of children who require specialized forms of transportation (e.g., who use wheelchairs). Rogozinski et al (2019) employ the term PCCI, for children

with pediatric chronic critical illness, or in other words that sub-group requiring the most clinical intervention, supports and resource use.

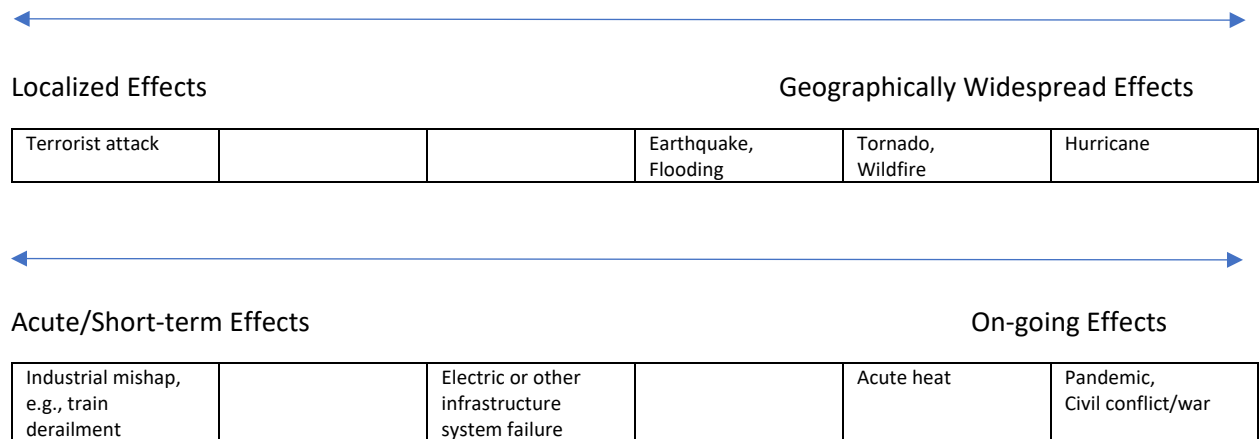
Disasters

For the purposes of this paper, our working definition of disaster is that of the International Federation of Red Cross/Red Crescent Societies: “A sudden, calamitous event that seriously disrupts the functioning of a community or society and causes human, material, and economic or environmental losses that exceed the community’s or society’s ability to cope using its own resources”

(<https://www.ifrc.org/en/what-we-do/disaster-management/about-disasters/what-is-a-disaster/>).

Disasters will vary by scale (wide-spread or localized), and duration (that is, they can occur in a short time span and be quickly resolved, or they may last over a prolonged period of time); they can come on suddenly, or evolve slowly over time, such as with the Covid-19 pandemic. They can be forewarned and anticipated, or occur relatively unexpectedly or with little lead time to prepare. Figure 1 below illustrates some of these dimensions, which have been used in the literature to create formal typologies of disaster events (e.g., Berren, Beigel and Ghertner, 1980).

FIGURE 1



These placings are illustrative, as disaster events obviously vary in magnitude, as seen for instance in the earthquake, hurricane or tornado intensity scales. Similarly, wildfires can affect different sizes of geographic area at any given time. The ongoing impacts also vary, depending upon the extent to which infrastructure such as electricity or water systems suffer damage. Highly destructive events will affect the health system’s ability to provide usual or alternative resources on a timely basis, and families may be displaced from their homes and communities for brief or extended periods of time. Key to disaster as we understand it, then, is that it is a mass event (not an individual medical crisis) and one which in addition disrupts the ability of individuals and families to access and receive care for a period of hours, days or longer.

Communication

Communication similarly can vary in a number of ways. For example, it can be **between professionals and a family or caregiver of a CMC, or peer-to-peer between professionals or among families**. It may

be one-way or two-way; direct or mediated (e.g., through an administrative assistant to parents, or through a caregiver to the children themselves); and need to involve only two parties, or multiple persons and organizations. It might be a one-time event, or involve regular and on-going contact and follow-up. Information can be transmitted orally, or in a written or recorded format; and delivered in real-time or exist as static resources that can be accessed asynchronously. It can be **reactive, or proactively** involve pushing information or reaching out and contacting patients following an emergency. It can communicate accurate information, or address and correct mis-information. It can be individualized and **tailored to an individual patient, or employ standard messaging** in mass or social media forms.

There is also variability in individuals' ability to receive materials by certain channels: this includes physical restrictions, e.g., hearing/vision impairment, but also social-technological barriers (e.g., lack of internet access or cell phone coverage). Such factors will need to be accounted for when determining what will be effective means and methods of communication during disasters.

We might also presume that the nature of communication challenges and needs would vary across types of disaster situation. One difference is the number of CMCs who would be impacted at once (placing different levels of demand upon professionals' time and attention). And of course, professionals themselves may be directly affected to different degrees. CMCs also have different types of needs (e.g., mechanical ventilation, specialized transportation, or specific nutrition) which may be provided at home, or require visits to a medical clinic or other facility. This can affect the content of what communication is needed during a disaster.

These ideas are usefully summarized in principles for effective disaster-related communication, as stated by Kailes and Lollar (2021):

“Information [should] be real, specific, and current. ... relevant information should be developed in partnership with people who live with disabilities ... [and] be made available in accessible, [multiple] and usable formats.” (p258-9).

These descriptors can be used to map the aspects of communication to which each article might provide useful data or lessons, as discussed in methods and results.

Methods

Standard approaches to conducting a rapid scoping review involve multiple steps, as most recently described by (Arksey and O'Malley, 2005; Levac et al, 2010; Peters et al., 2020). We carried out this review following the six steps defined below. 1. Define and align the objective(s) and question(s). 2. Develop and align the inclusion criteria with the objective(s) and question(s). 3. Searching for the evidence. 4. Selecting the evidence. 5. Extracting the evidence. 6. Analysis of the evidence.

1. Research question: The broad research topic for this review concerns how the health system communicates during times of crisis or disaster with families of CMCs. A previous scoping review on disaster information needs for CMC was published in 2018 (Hipper et al). Most of the publications identified in this review centered on wide scope of disaster planning and emergency preparedness, rather than focusing on communication during crises and in the

recovery and rebuilding phases. This review particularly investigates if further information has become available in the latter two areas. As well, it is expected that use of social media, and the COVID-19 pandemic will have generated additional publications not thoroughly considered before. This review is therefore an extension, rather than updating alone, of previous work.

2. Inclusion and exclusion criteria
 - a. Included papers were required to address both disaster/public emergency/mass casualty situations and children with special healthcare needs/medical complexity. See the section on search strategy, and appendices, for the operationalization of these concepts. Only English language papers were included.
 - b. Research protocols and individual case reports were excluded; but otherwise most article types were eligible for inclusion. As the review is interested in including publications written by or with direct involvement of family members or caregivers, this necessitates inclusion of paper types and sources normally excluded from systematic reviews (such as Hipper et al, 2018). Papers focused primarily upon planning for or responding to individual medical emergencies were excluded, as were papers which only described the physical or mental health effects of disaster. Children per se were not defined as a vulnerable population for this paper; the focus of the review is upon children with special needs who are at baseline community-dwelling, and so papers focused upon neo- or perinatal institutional care were excluded. We did not limit inclusion to only CMC, but included those with other functional needs or disability, so long as the findings appeared to be broadly applicable for the CMC population.
3. Search strategy: Two searches were run for the project. A health information specialist at BC Children's Hospital ran a search of Medline, CINAHL and grey literature in summer 2020. 59[?] publications were retained from this search for possible full text review. Based upon examination of these papers, a revised search was developed and completed by the Centre for Clinical Epidemiology and Evaluation (C2E2)'s health information specialist in spring 2021 in Medline, CINAHL, Embase, and Sociology Collection. Search strategies are reported in the Appendices.
4. Evidence selection: Titles and abstracts from the spring 2021 search were initially reviewed by one reviewer at C2E2. Those for which a clear inclusion or exclusion determination could not be quickly made were reviewed by a second reviewer, who used the same criteria to make a final determination as to whether or not full-text review seemed warranted. Articles identified for full text review were retrieved, where possible. Full texts were divided into two groups: COVID-19 related and other disasters. Articles in each group were read, and some further excluded at this point for not meeting inclusion criteria or being otherwise not relevant. After completion of this process, 26 articles were retained for data extraction. See the Appendices for PRISMA diagram (cf Page et al, 2021), and Figure X for disposition of full-texts within each category.
5. Data extraction. Categories in the data extraction template included year of publication; country; study design/article type; whether or not CMC were the primary focus; intervention (if any); types of qualitative and quantitative data collected and reported (if any); type of disaster; stage; key results; and any general comments and judgements related to relevance for the

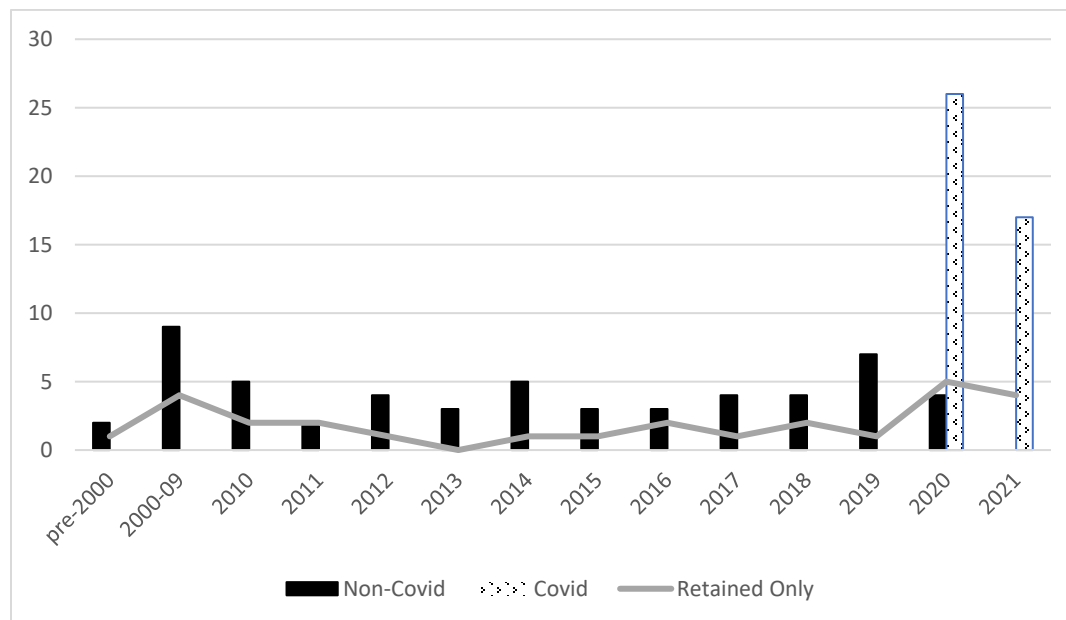
research question. Covid and non-covid papers were extracted in separate batches by different reviewers.

6. Data analysis. Since very few of the articles were explicit about the role of communications in disaster response –i.e., there was little manifest content (Berg,1989) -- we conducted latent content analysis, to identify and code blocks of text in which approaches to communication are alluded to, or can be seen occurring even if not remarked upon by study authors (Downe-Wamboldt, 1992; Hsieh & Shannon, 2005). In particular we apply latent projective analysis, looking beyond the text itself and drawing upon our own understanding of health and communication theories, as described above (Potter and Levine-Donnerstein, 1999).

RESULTS

A total of 26 full-texts were included in the review: 7 papers on Covid-19, and 19 papers on other forms of disaster or crisis. The following sections describe the findings from these 2 sets of papers; a narrative summary of each source is included in the Appendices. Countries represented were USA (13), or 50%, followed by Japan (3), New Zealand (2), France (2), Italy (2) and one each from Greece, Turkey, the UK and Australia; this includes both empirical and non-empirical studies. (The earlier Hipper systematic review reported 81% of papers, or 22 of 27, to be from the US context.) Considering publications by year (Figure 2 below) suggests a small but steady flow of articles potentially relevant to the topic of this review. Of the 26 retained paper, one-half (50%, n=13) were published between 2017-2021; 5 were published between 2012-2016, and the balance (n=8) were published more than 10 years ago. About one-quarter of papers (6/26) are published in journals or as a book specific to the field of disaster and emergency medicine, while the others target a range of generalist and specialist audiences of health professionals.

FIGURE 2: Full text articles retrieved, and retained, by year of publication



Twenty-one of the 26 papers were entirely or primarily about children with special needs. These were not limited to CMCs; for instance, some addressed children with sensory disorders, such as deafness (Rotondi et al, 2019; Mort, Rodríguez-Giralt, and Delicado, 2020), developmental disabilities, including autism (Dursun et a, 2020), and chronic diseases, e.g., diabetes (Stallwood, 2006). While it has been suggested that there may be structural program differences between care for children with a single defined illness or disease, and care for CMC, with the former focusing on disease management and the latter on care coordination (Meehan et al, 2019), we deemed that any information about communication strategies in the context of disaster would likely be transferrable. The five remaining papers included targeted comments about this group within the context of a larger discussion, project or study.

Table 1 below summarizes publications by disaster type and by the stage –planning, response or recovery – which is most substantially addressed within each.

TABLE 1: Retained papers by disaster type and stage

	All hazards	Earthquake	Hurricane	Pandemic
Planning	8	4	0	0
Response	0	1	1	7
Recovery	1	3	1	0

The largest proportion of the reviewed papers (12/26 papers, or 46%) focuses upon disaster planning and preparedness, though the relative proportion is skewed by the Covid-related literature; in this, our review finds the same as Hipper et al (in that work, slightly less than half of retained studies, 14/27, focused exclusively on preparedness, and only 4 papers had no focus on preparedness). Table 1 also indicates, again consistent with Hipper et al, that much of the disaster (planning and preparation) literature is all-hazard. In this review, that category accounts for 8/26 (or 31%), compared with findings in Hipper et al of 19/27 papers, or 70%.

Baker, Baker and Flagg (2012) note that the ‘all-hazards’ approach is recommended for disaster preparedness (p. 418) and that specific tailoring may be unnecessary (2010), though by contrast, Chang et al (2017) suggest that tailoring should be considered after initial disaster planning based on the all-hazards model. Drexel University’s Centre for Public Health Readiness and Communication provides tailored checklists, because they heard this request from parents (<https://drexel.edu/dornsife/research/centers-programs-projects/center-for-public-health-readiness-communication/disaster-preparedness-toolkit/>). Similarly, resources for talking with children after particular types of disasters (e.g., earthquakes, hurricanes and tornados) are offered by the Treatment and Services Adaptation Centre, <https://traumaawareschools.org/tsaResources/resourcecenter>, though these are not specific to CMC.

In the context of the authors’ location, British Columbia, Canada, earthquakes and tsunami, other floods and wildfires, avalanche or landslide may be the most likely natural disaster scenarios, along with pandemic disease outbreaks such as COVID-19 (see, for instance,

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<https://www2.gov.bc.ca/gov/content/safety/emergency-preparedness-response-recovery/preparedbc/know-your-hazards>).

A variety of research designs are used in the retained publications; it is possible for a paper to use more than one of the listed designs, so the total exceeds 100%. This review found 19/26 papers (74%) to include original qualitative or quantitative research; Hipper et al's review (2018) included 12/27 original research papers (44%).

- Survey=13
- Case study/description=7
- Commentary=4
- Interventional=3
- Literature review/synthesis=3
- Qualitative design=3
- Document review=1

Where original data was collected in most cases it was from the parents or caregivers of children with access and functional needs. In three cases, researchers worked directly with the children or youth. In some articles, the study population was not clearly described. In one case, websites and resource materials were the subject of data collection and analysis. Articles were directed at a variety of provider/practitioner audiences, including primary care physicians/medical homes, specialty care (e.g., nephrology, oncology), occupational therapists, speech language pathologists, social workers, school nurses and other educators, and emergency responders and transporters. The lead author in the majority of cases (n=14) was an academic-clinician, i.e., someone working at a university or teaching hospital. For remaining papers, the lead authors were, respectively, academics working in a non-clinical university department (n=5), community-based clinicians (n=3), government employees (n=2), not-for-profit organizations (n=1) and parents (n=1).

Communication-related content of the papers, whether manifest or (more commonly) latent, is categorized in Table 2. As the table suggests, there is some recognition of the value of proactive outreach at the time of a disaster, though the issue mostly is not evidently addressed. Most papers consider communication between health care professionals and families/caregivers, with a smaller number focused upon communicating with CMC directly. Typically, only one-way communication is described, though implicitly there is often back-and-forth among health professionals and families. Communication is typically in the form of mass or standardized products, with only a few papers describing approaches with some degree of targeting or tailoring to the specific circumstances of the families involved. Finally, while social media is a growing aspect of disaster response, only a few of the more recently published articles contain either brief or detailed description of how this can be or is used for communication during emergency or crisis circumstances.

TABLE 2—Communications

Proactive Outreach at the time of Disaster	Demonstrated 2	Called For 5	Not present 19
Directionality of Communication	Between Health Professionals and Families or Caregivers 18	Explicitly and Primarily Directed at CMC 3	Peer-Peer Among Families or Communities 5
Messaging	Standardized Messaging 7	Tailored or Targeted Messaging 8	Not addressed 11
Social Media	Used 4	Acknowledged, not used or studied 1	Not present 21

Thematic Results

Four themes arising from the data synthesis for this review are reported below. While these summaries draw primarily upon the 26 retained papers, additional support from the literature is identified where it was obtained as part of the overall research approach. Consistent with the intent of this review, three of the four themes address disaster response or recovery, while only the first one has a planning and preparedness focus.

Theme One: Cooperative and Collaborative **Planning**

- Pre-disaster, there is a need for **cooperative planning** with families (e.g. Campbell et al, 2009; Chin et al, 2020) as well as professionals and other stakeholders (e.g., schools, utility companies etc.). Ideally communicative approaches will include children themselves as well as parents or caregivers (Hipper et al, 2018) -- Sever, Sever and Vanholder (2020) says ‘listen to the children themselves’. Ronoh, Gaillard and Marlowe (2017) give concrete methods of involving children; see also sections in Mort et al (2020). Ronoh, Gaillard and Marlowe (2017) argue that the prospect of children being separated from responsible adults during times of emergency provides a good reason why they should be directly involved in planning. Darlington et al (2021) indicate a prime role for parents as co-producers of their Covid survey, and follow-up actions resulting from it.
- The literature notes a lack of **online disaster planning resources** targeting the CSHCN or CMC community. For instance, Koeffler et al (2019) found that only 36% of resources had a focus on children with special needs; gaps were perceived in short and concise materials, non-English materials. Chin et al (2020) also make a similar statement to this effect. These claims are consistent with So et al’s empirical findings (2020). Darlington et al (2021) and Huesler et al (2021) report COVID-19 survey-based data supportive of the same conclusion. There is also a lack of information and communication material aimed at children themselves (So et al, 2020)

- A key point in planning is the **two-way accessibility of information**. This means, to begin, having patient information accessible to professionals and responders. For instance, the value in having portable medical info, such as the emergency information form (EIF), in both electronic and hard-copy formats recurs in several papers (Goodhue et al, 2016; Kaziny, 2014; Mace et al, 2010; Murray, 2011). On the other side, parents, caregivers and children need to know how to reach their care team, including when usual channels of physical and telecommunication access are disrupted; this indicates the importance of having direct contact information (see Raulji et al, 2018, for instance). There can be substantial difficulties in communicating during disaster with children having certain types of sensory or intellectual challenge (Asher & Pollak, 2009; Boon, Brown, Clark et al, 2011; Quinn and Stuart, 2010).

Theme Two: Pro-Active Outreach, Engagement and **Response**

- **Proactive outreach** by professionals when a disaster is anticipated or occurring is recommended (e.g., Kaziny, 2014; Hassinger and Lail, 2021). One example of a proactive approach is described by Hoffman et al (2018), including a patient telephone contact algorithm; proactivity is also at least implied in the Taddei & Bulgheroni (2020) piece on Italy's response to COVID-19. Darlington et al (2021) noted from survey data that many parents did feel that inadequate information was offered by their hospitals or clinical teams. Most post-disaster empirical papers seem to describe responses which begin with reactive communication. For instance, Dozières-Puyravel and Auvin (2021) describe parent-initiated emails preceding a COVID-19 induced transition to virtual care processes. Health system response also is triggered by patients showing up at hospitals (Nakayama et al, 2014). Gillen & Morris (2019) suggest that this is a strategy many parents may in fact have in mind as part of their own disaster response plan. Sakashita, Matthews, and Yamamoto (2013) argue that this is "an inadequate plan". One strategy that is suggested is having a designated point person or **care coordinator** who is aware of service structure during a disaster and can connect parents and children to their needed care (e.g., Dursun et al, 2020; Cacioppo et al, 2021). A Canadian study, in a non-disaster context, looked at the employment of nurse-practitioners to promote care integration for CMCs (Lin et al, 2021). In the US, some authors suggest that CMCs should have a primary care patient medical home (Cohen et al, 2011; Kaziny, 2014) which can serve this purpose, so long as the practice is prepared for disaster response, of course.
- Information can go out by mass or individualized channels, with greater proactivity clearly required for the latter. **Social media** platforms straddle those boundaries perhaps. While social media has vastly expanded its role and influence in life, there has been yet limited research on its use by CMCs in disaster situations to date. So et al (2020) note their exclusion of social media and peer forums as sources of disaster planning information as one limitation to their research. Rotondi et al (2019) is one specific example of Facebook use. Social media is identified by parents as a channel of preferred communication (Hipper et al, 2018) and has been a main source of information for parents of CMC during the COVID-19 pandemic (Darlington et al, 2021). However, in the words of one parent, "sometimes having all this information on the internet is a blessing and curse" (Hassinger & Lail, 2021). Social media is also potentially a significant source of mis-information (Zhang et al, 2019), as seen in the spread of 'fake news' related to the COVID-19 pandemic (Atehortua and Patino, 2021). The research by Darlington et al (2021) noted that although many parents reported social media as a major source of

information during the pandemic, far fewer stated that they used that information to make decisions or placed their full faith in it. This is consistent with the larger literature, for which a review concludes that social media is not the primary information source for most members of the public (Zhang et al, 2019). However, mixed messaging from health sector sources can itself also be a problem in communicating with the caregivers of CMCs during a crisis (Darlington et al, 2021; Hassinger & Lail, 2021).

Theme Three: Mobilizing and working through Social Networks in **Response**

- Proactive reaching out, by peers, can form most immediate response, as for instance described in at least one Japanese case (Shimada and Funato, 1995). Quinn & Stuart (2010) also identify the importance of **personal networks** as first responders. A similar claim is made, albeit not specific to children, by Kailes and Lollar (2021). The importance of engaging neighbours is also stated by Sakashita, Matthews, and Yamamoto (2013), and Rau (2021). In fact, “operators and practitioners tend to rely on the relatives of people with disabilities to disseminate specific information” (Rotondi et al, 2019). Hassinger & Lail (2021) recommends “including functional community members” e.g., teachers, friends, etc., as part of planning. However, in Chin et al (2020), focus group participants reported “difficulty in building meaningful relationships with their neighbors.... parents were unsure of their willingness to help, and did not feel empowered to start those discussions.” (p192).

Theme Four: **Recovery**

- Continuity of care is important to reestablish (Ireton-Jones, Nishikawa & Nishikawa, 2019) during or post-disaster, which may involve transitioning to **telehealth**, mHealth [mobile health], or other internet-enabled communication channels, as was the case in many places where in-person care was restricted due to COVID-19 (for instance, Taddei & Bulgheroni, 2020; Hassinger & Lail, 2021). However, we cannot forget that not all CMCs will have ready access to the technology needed, especially during disaster disruptions; there is data on this provided by Hassinger & Lail (2021) and Murphy et al (2021), as well as case discussions from European responses to COVID-19 (Cacioppo et al, 2021, Taddei & Bulgheroni, 2020). Disasters also present mental health impacts, as well as disruptions to physical care and treatment. The COVID-19 pandemic has demonstrated these in the short- and medium-term (Taddei & Bulgheroni, 2020; Dursun et al, 2020; Cacioppo et al, 2021). In addition, the response and recovery phases are where longer-term **mental health** issues, among CMCs and also their caregivers and siblings, will emerge (Peek & Stough, 2010; Stough, Ducey and Kang, 2017). These have not been extensively studied among CSHCN (Boon, Brown, Clark, 2011). Care teams may need to expand to adequately and fully address such issues (See for instance, Takada 2013; Dursun et al, 2020; Murray, 2011).
- Of note, re-establishing normal daily life for CMC includes resumption of **disrupted schooling** as well as healthcare specific programs and services. As Boon, Brown, Tsey et al (2011) state and as the COVID-19 situation has demonstrated, school closures can be “an important non-pharmaceutical component of controlling outbreaks of infectious diseases such as pandemic influenza, although little research appears to have been done on the effect of such closures”. This clearly matters to the children themselves: “Rather presciently [in re COVID-19], children ... [with disability] in Greece drew our attention to how disruption of normal life, the impossibility

of leaving the house to play or attend school, would be for them a disaster” (Mort et al, 2020, p157). Some additional support for this point is offered by Ducey and Stough (pre-print). Canadian experience appears to be consistent with this as well; a survey of Canadian pediatricians reports that many CMC receive care and therapy in the school setting, and that few of these were able to access such resources during the school closures brought about in response to the COVID-19 pandemic (Diskin et al, unpublished manuscript). While multiple school years have been affected by COVID-19, parents and CMC have been able to remain in their homes; additional challenges are encountered where disaster leads to longer-term evacuation and displacement, as for instance with wildfire or flooding (National Collaborating Centres for Public Health, 2021).

Patient Partner Feedback

Two patient partners, both parents of CMC, were engaged to provide feedback on the draft report summary and the Vignette (following); both were compensated for their time in accord with the funders’ guidelines (SPOR Evidence Alliance, 2019). These parents provided helpful feedback during a real-time virtual meeting and subsequently via email, and improvements to this report were made in consequence. Both parents also provided individual reflections upon the experience and their views about the findings: these are included below, unedited by the research team.

Parent 1

If there is a disaster, what about children with medical complexity? I agree with the *thematic findings.* I am glad to see that co-operative and collaborative planning is emphasized. We often skip detailed planning for disasters as if they will never happen. I think that a key to this preparation is creating awareness of the potential risks and need for precautions for children with medical complexity. The consumers’ families, healthcare and other potential first responders definitely will benefit the consumer by being aware, planning and being proactive before or during disasters. Many people will go about their daily lives, without paying attention to some potential risks, because daily life is so hard already and we may not want the extra “work” of planning. For healthcare and academia to find ways to reach out and support these families seems so important to me, for the children, because the children and their families may not be able to reach out on their own. Mobilizing social network apps, and strengthening communications to all consumers, their families and first responders, seems like an extremely important area for development. I see a greater need for continuity in data bases and information accessibility in crisis situations. The third theme resonates with me as well, again pointing to the need for proactivity and awareness among first responders and communities. I also appreciate the emphasis in the fourth theme of disaster recovery. We can’t forget about those that need our help most, just because some of our own “conveniences” have not been restored. Children of medical complexity and their families may be in dire need before, during and after a disaster. I totally agree with the focus on communications and accessibility of support for all community members, and prioritizing those that need the most help, first.

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I am glad to have been able to provide some views for your research. The topic is very relevant in today's world and I can also see a need for progress in this area. Thank you for helping to make that difference!

Parent 2

The report 'Communication in disasters to support families with children with medical complexity and special healthcare needs: A rapid scoping review' is a timely and informative review of the present and unfortunately, rising challenges that families with CAFN are facing. As the uncertainties of economics and healthcare delivery due to the pandemic loom, the possibility of the concerned families falling through the cracks of the system is becoming glaringly obvious. Unfortunately, personal experience and anecdotal information seem to relay the message that there is very little reliable information available for such families within the healthcare systems to address any challenges should disasters strike. The report provides a strong case that resounds with the concerns of the families, which can be further strengthened by including more families in the policymaking process, such as interviews and surveys.

We see the report as a living document with many parts evolving from it. Some of these include ensuring the economic and physical safety of the families affected, and methods to make access to resources, services, medication, healthcare delivery, and recovery an easy to access process. Further, there is a need for concrete step-by-step protocols, and ensuring families are educated actively about their options, and not simply relying on website content as a means of communication. Finally, digital technology should be included for the safety and protection of patient data and access in the event the patient is unable to communicate their health concerns (child, elderly, infirm, mentally challenged, etc.), as well as communication with central bodies, personnel, institutions, or local officers, to help coordinate efforts.

We hope this report will pave the way for families that are heavily burdened by the challenge of caring for their loved ones while trying to navigate difficult systems. We hope that our contribution as patient partners helped in providing perspectives from the patient's end, and help provide a voice to the vulnerable in this complex discussion.

Conclusions

The topic of communication with CMC during disaster crosses quite a heterogenous literature, which makes it challenging to synthesize. It is unclear, for instance, the extent to which varying definitions of the target population will affect the findings. It does seem safe to say that, consistent with previous reviews, the literature remains focused on preparedness, primarily employing an all-hazards approach. There is also a lack of literature and on-line resources specific to disaster preparedness and response for children with special health care needs and their families.

Overall, there is little explicit data about effective approaches to communication; this requires us to 'read between the lines' and identify latent content related to how communication is (and isn't) being addressed, the assumptions being made, and the gaps or lacuna. There are little grounds for proposing rigid set of specific best practices (do X for group Y in situation Z). Instead, illustrative vignettes can

depict how disaster response might play out in particular situations. This approach was used in some articles reviewed in this project (e.g., Asher & Pollak, 2019; Murray, 2011); for other examples, see <https://www.cdc.gov/childrenindisasters/real-stories/specialneeds/index.html>. We offer here, tailored to the BC context, one scenario of how communication with CMC might proceed during times of disaster, emergency or crisis.

British Columbia. Late-June 2022. A dry winter has been followed by a spring heat wave. While children are looking forward to the final weeks of school, in several small- and medium-sized communities, the fire danger has been raised to ‘extreme’, with thunderstorms and lightning in the weather forecasts. It is anticipated that uncontrolled fires may necessitate emergency evacuations.

Planning. Recognizing this, primary care providers (family physicians and nurse practitioners) and pediatricians whose patients include CMC put into effect the outreach plans which they’ve developed together with specialty care team members in case of emergency. A designated team coordinator contacts every family of CMC on the practice roster to make sure they are aware of the potential disaster, and advise (and guide) them on municipal evacuation plans. They check with the families to make sure each has its own individual disaster plan up-to-date as well, and are prepared to self-manage for a time if they may have to. The coordinators also contact mental health providers with whom they have arrangements, to confirm that their services are in place and ready to activate if needed.

Response. Several days of lightning and high wind combined with minimal rainfall have sparked fires across large sections of the province. Some have been successfully knocked back with aggressive actions, others are contained, but a couple of fires in steep terrain have taken off and evacuation orders have been issued for a number of communities. Time is of the essence. Clinical teams are in frantic conversation as they reach out to re-connect with families, to let them know about the status of community services. The remainder of school terms have been cancelled, community health facilities are shuttered, and several family physicians are preparing to evacuate themselves.

Case coordinators keep families up-to-date with these developments, work with them to determine evacuation routes, and identify shelters which can provide key resources, such as emergency generators, medical supplies, clean water, milk for babies, and wheelchairs. Where needed, they call on contacts who understand the province-wide picture, and know which stockpiles of supplies can be moved from one site to the next. Trusted local professionals on-the-ground provide real-time updates through their official social media platforms; these complement media updates provide by health and local government sources. Families of CMC are linking with neighbours who can provide accessible transportation, satellite phone connections, and other resources.

Recovery. Some fires are quickly knocked down, while others rage into mid-August, putting families out of their homes for six weeks or more. Some communities are heavily impacted with extensive damage, others less so, but finally evacuation alerts are lifted and residents can return home. For the lucky ones, the biggest task is disposing of

a freezer-full of spoiled food. In other communities, homes, schools and public facilities are gone, electric grids destroyed and running water limited or unavailable altogether. Before going anywhere, families of CMC discuss circumstances with their health provider team: where will they reside, how will they communicate with CMC, who in the vicinity can help them, which public services will resume locally and when, and which ones may be available in neighbouring towns? Tele-health options have been established by many health professionals; special attention is paid to ensuring that parents and caregivers are aware of and have the resources to access these services.

Autumn comes, and things begin to return somewhat 'back to normal' for most – fire season is over, they have returned to their homes, and schools and other services resume. A few families, however, will remain displaced for months yet. They work with their provider teams to link to interim supports, and use the internet and other means to stay connected with the community and maintain social relationships.

Health professionals and the families discuss their experiences (with appropriate mental health supports available), and gather feedback about lessons learned and how to improve disaster response in the future.

In summary, based on the data identified, we offer these recommendations for advancing current approaches to disaster communication for CMC and their families:

- Directly engage with parents and children to advocate to policy makers the importance of establishing processes for two-way communication to prepare for disasters, with emphasis on equity despite location and language differences.
- Explore the best means for families and health care teams to leverage personal/social networks in communication.
- Implement proactive outreach, in advance of an expected disaster where lead time is available, and also in the immediate response phase. This seems easiest to do where an existing registry or inventory of the population of CMC can be deployed.
- Maintain two-way communication channels following disaster, including the use of multiple methods and redundant channels (e.g, deploy both electronic and hard-copy formats)
- Investigate and experiment with social media channels as a messaging approach; this includes efforts by reputable and trusted health care sources to counter mis-information which may be prevalent in some social media platforms. Do this in real time if possible.
- Provide information about how continuity of care will be ensured during disaster response. Telehealth or telemedicine services is one means by which this can be done. The COVID-19 pandemic produced a rapid outpouring of literature on this. While it seems to have largely satisfied families' needs, there are access and equity issues. The lack of children's presence in telehealth consult sessions, as explicitly identified in 2 studies, is worrisome insofar as we are thinking elsewhere in findings about the importance of directly engaging children/youth. It will be important to use virtual care mindfully and effectively, with acknowledgement that there yet lack any established quality standards.
- Pay attention to mental health (and rehabilitation) aspects in the longer-term recovery phase; this may imply expanding the scope of the patient care team.

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These communications-related recommendations apply beyond disaster situations as well; they reflect principles of proactive child-centred healthcare. If the ongoing relationship between parents and caregivers, children, and health professionals is running smoothly, then it should be much easier to manage the disruptions which result from if or when disaster strikes.

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APPENDIX A

Summaries of relevant articles, with emphasis on what they say about communication

Authors & Date	Title	Summary
Asher & Pollak, 2009	<i>Planning Emergency Evacuations for Students with Unique Needs-- Role of Occupational Therapy</i>	This study focused on disaster and emergency planning at schools, using case examples. The tool is a written individualized evacuation plan, the nature of which is described in some detail (which may help inform development of other communication materials). As one part of the document, specific key and backup contacts are identified. Family members and professionals are directly involved in plan development. Notes that CMCs may have specific challenges in communicating, which need to be accounted for. This article addresses only a moment in time during an actual disaster, and ends at the point where students have been evacuated from a school building.
Baker et al, 2012	<i>Preparing families of children with special health care needs for disasters: an education intervention</i>	This study was undertaken with a convenience sample of parents/guardians of children with chronic medical conditions seen at one US children's hospital. The intervention was a one-to-one education session, which consisted of discussion plus distribution (in paper copy) of informational handouts. Content was generic rather than tailored to individual medical conditions. Authors favour this approach over mass media, which they suggest has unknown effectiveness (though not cited); this approach mobilizes "informal social context". Healthcare professionals presumed to be trusted sources of information.
Cacioppo et al, 2021	<i>Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: The ECHO French survey</i>	This nation-wide survey describes an array of channels used to promote the survey (email and social media; via parent groups, advocacy groups and professional networks). Major impacts include loss of social contacts leading to negative moods and behavioural problems, and disruption in education and health care services. Parents reported greatest concerns with rehabilitation rather than medical issues (perhaps reflective of the degree of disability, but not stated). Parents have greatly increased burden, having to perform a lot of services usually done by skilled professionals. Discusses need/value of creating a 'care coordinator' position for clients.
Chin et al, 2020	<i>A mixed-method analysis: Disaster preparedness of families with children with access and functional needs</i>	A questionnaire and focus group study with 20 parents of CAFN (children with access and functional needs) in California. Consistent with other literature, found relatively low levels of preparedness, though parents anticipated several types of disasters were more likely than not to occur. Communication as an issue was raised with respect to schools, as well as

		neighbours. Does not address any recommendations or suggestions for improvement however.
Darlington et al, 2021	<i>COVID-19 and children with cancer: Parents' experiences, anxieties and support needs</i>	Reports a UK-based survey of parents of children with cancer (N=171), initiated by 2 health centres and circulated through networks of professional organizations, health charities. (Notes that these groups regularly updated and disseminated the latest Covid advice through their channels.) Parents were involved in developing the instrument. Two parts: close-ended and open-ended. Emphasis on social media; for instance, notes that parents were expressing fears via social media groups. In the quantitative data, it was observed that 49% got information from their clinical team, while 84% got information from social media; smaller numbers of people stated that social media was influencing their decisions (25%) and few trusted it (8%). In the qualitative content analysis (N=130), it is noted that some parents avoided news or social media as a coping strategy. Other qualitative results were that parents found a lack of information targeted to children with disabilities (rather than the general adult population), and that they found their teams/hospitals not to be providing enough information; more guidance and support was desired. Mixed or changing messaging was also a problem. Among the subgroup who responded with open feedback, the main sources of information were health charities, clinical staff, and the news. Concludes by stating that the feedback was directly translated into action, for instance through co-creation of additional information distributed through the same professional organization, charity and local provider networks (not described in detail).
Dozieres-Puyravel et al, 2021	<i>Usefulness, limitations, and parental opinion about teleconsultation for rare pediatric epilepsies</i>	This reports on use of telehealth in one French hospital centre during the COVID-19 pandemic. Notes that the service was completely not set up prior to the pandemic to do any virtual health consultations. Contacts appear to involve parents initially reaching out by email, with questions or issues for the care team; by the time virtual services were set up, most had done this. Most done by audiovisual, some by phone largely due to difficulties with the technology, or parents' fear/anxiety. Suggests looking for ways to substitute lack of physical exams and observation. Noted that the children often were not part of the sessions, reasons unexplained.
Dursun et al, 2020	<i>Caring for the Most Vulnerable: A Model for Managing Maladaptive Behavior in Children with Mental Special</i>	Focus on children with mental impairments (e.g., autism) in Turkey. Built an all-new nation-wide system involving care coordinators with videoconferencing, and local "psychosocial intervention teams" [new type of provider] for more complex cases. Based on a mobile app with 24/7 live response. Unclear why the parents regular care team was not a first point of contact? The service was advertised with a news conference

	<i>Needs During the COVID-19 Pandemic</i>	and information to local provider organizations; presumably media but no additional details. Social isolation etc. due to Covid giving parents concern with maladaptive behaviours; a new concern and one more pressing than physical health.
Goodhue et al, 2016	<i>Mixed-Methods Pilot Study: Disaster Preparedness of Families with Children Followed in an Intestinal Rehabilitation Clinic</i>	This study focused on disaster planning, with earthquakes as a particular example. Research involved a convenience sample with a survey and 2 focus groups; English only. As far as preparation, a majority had some form of back-up for power and medical supplies, but almost none had an emergency information form (EIF). Communication was anticipated by parents to be them reaching out, by attending a hospital when supplies were exhausted. However, they also reported from past experience that professionals unfamiliar with their children’s conditions could be unhelpful. Having direct contact information was important (physicians, also pharmacy, insurance, utility cost.) It was seen as helpful if professionals gave written letters or other information detailing medical conditions/needs. Communication also incidentally in the research through peer-to-peer interaction in the focus groups, with some parents sharing preparedness ideas.
Haeusler et al, 2021	<i>Managing low-risk febrile neutropenia in children in the time of COVID-19: What matters to parents and clinicians</i>	This study is in context of efforts to develop a home-based program in Australia for children with febrile neutropenia [cancer]. The relevant portion is results of a parent survey (n=14) using an adaptation of the ECOM (Effective Communication in Outbreak Management for Europe) instrument. Findings: “Communication that parents wanted to receive about COVID-19 included information about ‘chance COVID-19 is serious for child’ (n = 7), how is it treated (n = 7), safe return to school (n = 5) and illness prevention (n = 5). Communication around mode of transmission, incubation and symptoms were infrequently identified as important factors. All parents reported they preferred information provided by their oncologist, followed by state/federal governments. Qualitative comments highlighted a need to address the availability of information tailored to children with cancer including those off treatment, as well as more consideration given to return to school advice for regions with higher community transmission”.
Hassinger and Lail, 2021	<i>PANDEMIC IS DECLARED: Early Experience from Families of Children with Medical Complexity during SARS-COV-2</i>	This is largely a story of one family’s experience, with some additional literature and recommendations for systems change. Themes include supply chain disruptions; communication challenges, including mixed messaging; behavioural health impacts; disruptions to school-based and other allied health services; and use of telehealth as a substitute for in-person care. Recommends proactive outreach

	<i>Lockdown: Information to Drive System Change</i>	in a couple of spots, and the importance of multimodal communication.
Hoffman et al, 2018	<i>Hurricane Irma Impact on the Inpatient Population at a Tertiary Children's Hospital in Florida</i>	This is a case study of how one Children's tertiary care centre, in Orlando FL, responded to a hurricane event. The hospital remained open; it sheltered 13 patients in place and received 13 patient transfers. This covers planning and response. Notes that patients needed both scheduled and unscheduled care for conditions not related to the hurricane itself. Proactively identified vulnerable patients (those dependent on medical devices) and set aside space and staff for them. Notes that parents otherwise planned desperate measures, such as faking illness at a community hospital (p1397).
Kaziny, 2014	<i>The Prehospital Care of Children with Special Health Care Needs</i>	One section of this paper deals with disasters, covering both preparedness and response; the preparedness section largely summarizes other papers we have identified. There is a call for co-creation of EIFs. Also, "The prehospital provider should take a proactive role in reaching out to families with CSHCN in the case of a disaster to provide detailed information regarding the community's plan for disaster shelters and evacuation assistance." Pre-hospital provider is never clearly defined, but mostly seems to be EMT and transport.
Kobayashi et al (2016)	<i>The lack of antiepileptic drugs and worsening of seizures among physically handicapped patients with epilepsy during the Great East Japan Earthquake</i>	A survey of patients affected with epilepsy in the aftermath of a 2011 earthquake. Patients attend a Children's Rehabilitation Centre, though not all seem to be children. It is stated that hospital also provides transitional care for younger adults; the median age of those surveyed was 14, through the range was 4-38 (n=161, out of 279 eligible). Noted that telecommunication systems were down for 5 days; during this post-earthquake period, 29% of respondents ran out of needed medications, and of those, 46% were unable to contact the hospital centre. Important information about alternative means of accessing prescription medicine was conveyed by website; effectiveness of this was not assessed.
Mace et al, 2010	<i>Pediatric issues in disaster management, part 3: special healthcare needs patients and mental health issues.</i>	Summarizes some literature on CSHCNs and disasters. Like others, notes importance of EIF [and hard copy in the event of power failure], of engaging with community stakeholders (e.g., utility companies) for disaster planning. Conversations can be phrased using a requirements/gap analysis strategy. Suggests 'backpack' tag with info for children who may become separated from caregivers (e.g., during school evacuations). Use of 'message maps'. Mapping of patient home location using Geographic Information Systems. One of a series of 4 articles (but maybe the only one with this focus).

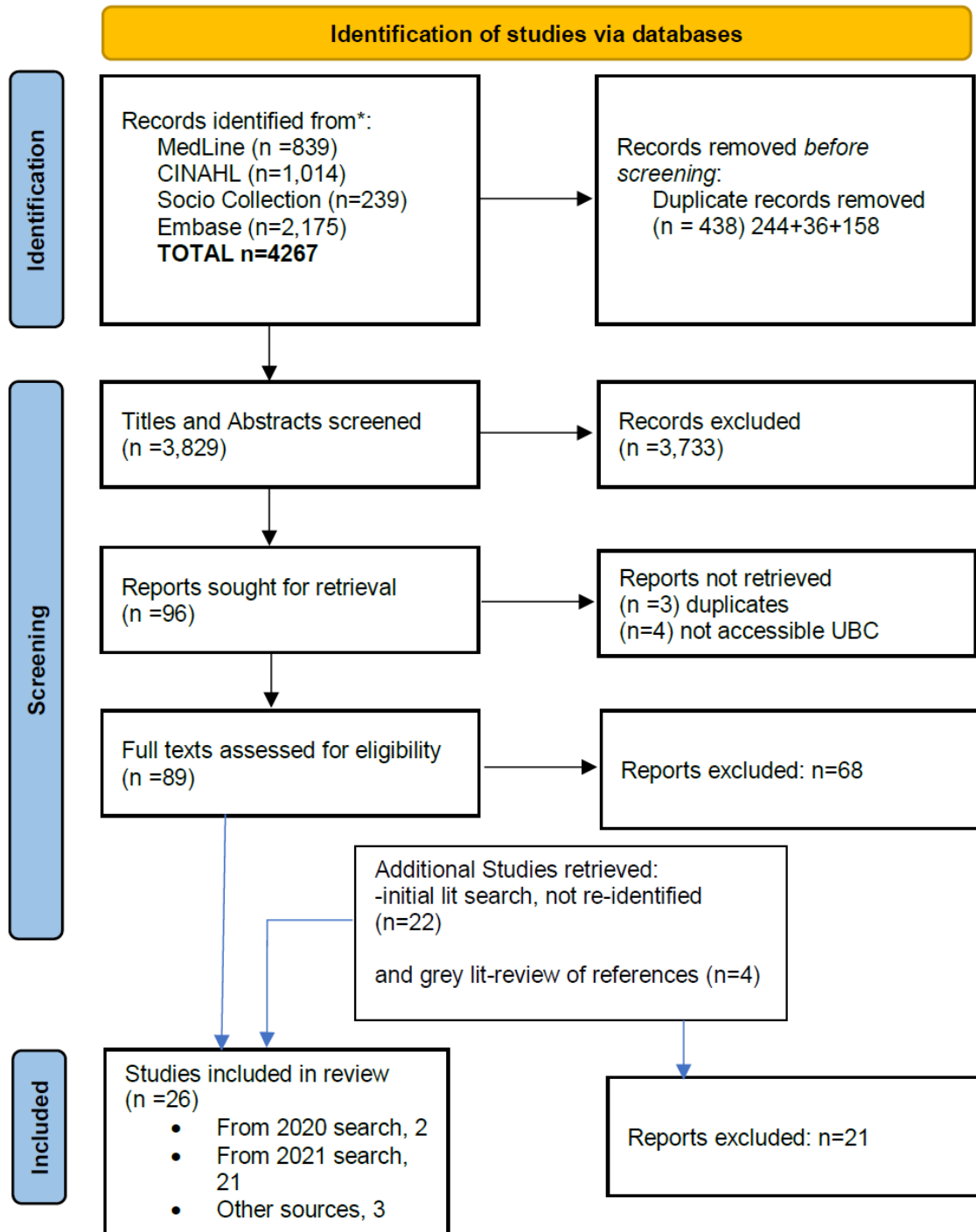
<p>Mort et al, 2020 [Edited book]</p>	<p><i>Children and young people’s participation in disaster risk reduction: Agency and Resilience</i></p>	<p>This edited collection reports the CUIDAR project (Cultures of Disaster Resilience Among Children and Young People), a pan-European project implemented in 5 countries, which conducted Dialogues with Children using a rights-based framework. The Greek component (n=63) specifically involved children with sensory (vision, hearing) and multiple disabilities. 3D modeling is a technique described (p124).</p>
<p>Murray, 2011</p>	<p><i>Disaster preparedness for children with special healthcare needs and disabilities</i></p>	<p>Mostly addresses preparedness; refers to a systematic review though this paper is presented as ‘Ask the expert’ rather than a traditional academic article reporting those results. Argues for parental involvement with professionals in developing emergency plans, and that children should have direct access to materials at an appropriate developmental level, sharing feelings and asking questions. Notes there may be misinformation (in context of those with cognitive impairment particularly). Recommends use of an emergency information form, per the AAP 2010 policy statement; ideally in electronic form as paper records can be lost, and where parents can’t access usual professionals, emergency departments may not have access to medical records during disaster. Addresses long-term psychosocial aspects. Potential separation from parents during disaster. Challenge of coordinating multiple specialists. Role of utility companies.</p>
<p>Nakayama et al, 2014</p>	<p><i>Effect of a blackout in pediatric patients with home medical devices during the 2011 eastern Japan earthquake</i></p>	<p>This study focused on post-disaster treatment. Communication explicitly identified as problematic in earthquake aftermath for these families. Research involved review of medical records, and patient questionnaire. Communication involved patients reaching out by showing up at regional medical centre (which escaped damage) due to being without power/supplies or running out of them. Often this was unannounced as patients unable to make contact. Transport also identified as a problem due to gasoline shortages (84%). Recommends re. communication for preparedness (1) info sharing among medical centres and local government; (2) portable personal medical information documentation; (3) availability of contact numbers. Text and cellphone communication reportedly superior to regular telephone in the post-earthquake conditions (though this is literature from another study and not investigated here).</p>
<p>Quinn, 2010</p>	<p><i>Disaster Preparedness</i></p>	<p>This article is directed at speech-language pathologists and focuses upon children with “complex communication needs” (which may or may not overlap with CMC, unclear). The paper provides summary findings from a literature review, and a sparsely detailed description of a ‘community outreach’</p>

		<p>program related to children with CCN. The audience appears to be parents and/or first responders ('community stakeholders'), but unclear. Literature review notes importance of personal social networks.</p>
<p>Raulji et al, 2018</p>	<p><i>Impact of Hurricane Katrina on healthcare delivery for New Orleans patients, 2005–2014</i></p>	<p>A children's hospital in New Orleans surveyed patients in the pediatric hematology and cancer program one-year post Hurricane Katrina; on the basis of feedback a Hurricane Action Plan was developed and implemented, and a follow-up survey conducted in 2012-13 with patients seen during those years, to assess program impacts. In 2006, not knowing where to get care, if the hospital was open [it was], and how to contact specialist professionals, were barriers to accessing care. The Action Plan involved providing patients with a treatment-during-disaster/evacuation roadmap and contact information. Evaluation found that, at the time of the second survey, "Only 29 (36%) had their roadmap/treatment plan available with them ... [and] Although emergency contact for the child's hematology/oncology staff had been given to all the patients, only 57 (72%) reported they had the information available with them." Communication seems to involve providing pamphlets. Providing info to families on flash drives was recommended by some survey respondents.</p>
<p>Ronoh et al, 2015; 2017</p>	<p><i>Children with disabilities and disaster preparedness: A case study of Christchurch</i></p> <p>AND</p> <p><i>Bridging the Participatory Gap: Children with Disabilities and Disaster Risk Reduction</i></p>	<p>Two papers: the first is a case study on working with children with disabilities in one Christchurch school on disaster response planning activities; the second extends the work to two additional schools. Provides concrete and detailed description of tools that can be used to engage children with disabilities in disaster planning. The 2015 paper uses Christchurch earthquakes of 2010 and 2011 as specific background, with comments on telecommunications issues that arose.</p>
<p>Rotondi, 2019</p>	<p><i>Facebook page created soon after the Amatrice Earthquake for deaf adults and children, families, and caregivers provides an easy communication tool</i></p>	<p>Notes that there was limited data to identify the relevant population that was or might be affected (the lack of a unified standard definition of CMC suggests a parallel issue). Authors created a page in the aftermath of the disaster; prioritized timely translation of official and credible information. Concludes that, "a well-received social question-answer service could help to spread information on safety practices in a day-to-day, easy, and affordable way". Includes children as target audience but not specifically focused on them.</p>

	<i>and social satisfaction in maxi-emergencies</i>	
Shimada and Funato, 1995	<i>Home mechanical ventilation in the aftermath of the Hanjin-Awaji earthquake disaster</i>	A questionnaire study of caregivers 1-month post-earthquake. Peer-to-peer communication features prominently. "During the first days immediately afterwards, neighbors were the most helpful persons available. After the earthquake, the importance of the establishment and maintenance of good communication with neighbors became more important than ever". Also important was role of the Baku Baku club (network among parents of CMCs), which appears to proactively reach out to members and to bring resupplies. Recommends a registration system for home care patients.
So et al, 2020	<i>An Evaluation of the Literacy Demands of Online Natural Disaster Preparedness Materials for Families</i>	This paper attempted to identify free, online disaster preparedness learning materials which Americans would be likely to access, and to assess the literacy demands of these. A sub-section of the analysis is devoted to materials specifically directed to parents of CSHCN. This constituted 5% of the total (18 out of 356 websites). While the authors found overall the materials to be adequate to poor in terms of five measures of literacy level, materials specific to CSHCN fared somewhat better. Authors note that no materials are directed to children themselves as a target audience, and their research did not include direct parent/child perspectives, or capture other potential sources of online information such as social media. Interestingly, healthcare organizations did not produce or maintain any of the internet sources.
Stallwood et al, 2006	<i>Assessing Emergency Preparedness of Families Caring for Young Children with Diabetes and Other Chronic Illnesses</i>	This article advocates the importance of children with chronic diseases to use medical alert jewelry or other wearables, which can provide key information to responders during times of emergency. A number of methods of promoting this are mentioned. For instance, for children themselves, "posters, coloring books, age-appropriate video presentations in the waiting room, and the like can be displayed, promoting the important messages of emergency preparedness, along with examples of how to meet the needs of preparing such devices". Further, "Information sources specific for the caregiving adult should also be readily available. These sources may include brochures outlining Internet resources, a list of local vendors carrying the necessary equipment, informational videos related to the assembly and maintenance of emergency medical supplies, and the display of various medical alert identification schemes and a sample emergency kit." These are largely one-way communication; conversations (assisted by checklists) are also recommended for increasing individual preparedness.

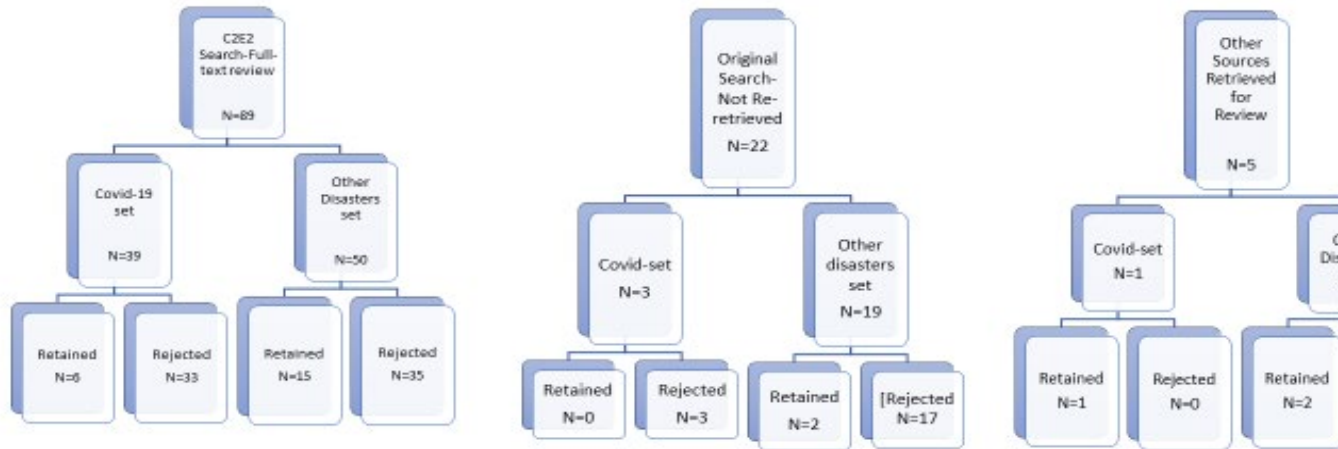
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Taddei and Bulgheroni, 2020	<i>Facing the real time challenges of the COVID-19 emergency for child neuropsychology service in Milan</i>	Most of the children here have developmental disabilities. Used phone contacts until telehealth services were ready, appears to be proactive, "we reach out to our patients" about the changes in hospital access being made. Did not require patients to download any app. Some technology issues with accessibility, and language barriers. Also notes the frequent absence of children from the sessions, reasons not explained. The pandemic is creating new issues for parents, more psychosocial and child behavior ones than the normal physical health matters dealt with during the former in-person visits.



Adapted From: <http://prisma-statement.org/prismastatement/flowdiagram.aspx>

Appendix C: Disposition of Full-texts



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Appendix D: Search Strategies

Spring 2021

MEDLINE Search – 2021 Disaster M5

Search was executed on: March 21, 2021

Search Strategy:

- 1 disasters/ or emergencies/ or mass casualty incidents/ (62003)
- 2 natural disasters/ or avalanches/ or cyclonic storms/ or droughts/ or earthquakes/ or floods/ or landslides/ or tidal waves/ or tornadoes/ or wildfires/ (18963)
- 3 Tsunamis/ (922)
- 4 Volcanic Eruptions/ (1098)
- 5 bushfire*.mp. (339)
- 6 Explosions/ (4049)
- 7 (avalanche* or cyclone* or drought* or earthquake* or flood* or landslide* or tidal wave* or tornado* or wildfire* or bushfire* or tsunami* or hurricane* or volcan* or explosion*).tw,kw,kf. (82476)
- 8 biohazard release/ or chemical hazard release/ (637)
- 9 radioactive hazard release/ or chernobyl nuclear accident/ or fukushima nuclear accident/ (7409)
- 10 terrorism/ or bioterrorism/ or chemical terrorism/ or september
- 11 terrorist attacks/ (11021)
- 11 (terrorism* or bioterrorism* or terrorist*).tw,kw,kf. (9687)
- 12 CBRN.mp. [Chemical, biological, radiological and nuclear defense] (204)
- 13 ((chemical or biological or radiological or nuclear) adj3 (warfare or incident* or accident*)).tw,kw,kf. (7982)
- 14 disease outbreaks/ or epidemics/ or pandemics/ (144217)
- 15 disease transmission, infectious/ (10457)
- 16 emergencies/ (41209)
- 17 (epidemic* or pandemic*).tw,kw,kf. (185277)
- 18 evacuat*.mp. (22160)

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- 19 ((national or global or community) adj5 (emerg* or outbreak*)).mp. (17117)
- 20 (exp hemorrhagic fevers, viral/ or hemorrhagic fever, ebola/) and outbreak*.mp. (7574)
- 21 ((Health* or infecti* or disease*) adj5 outbreak*).mp. (99403)
- 22 ((natural or health) adj5 catastrophe*).mp. (306)
- 23 Coronavirus Infections/ (44640)
- 24 Severe Acute Respiratory Syndrome/ (5490)
- 25 (coronavirus* or SARS* or COVID*).mp. (137295)
- 26 (pre-disaster* or disaster* or postdisaster*).tw,kw,kf. (27906)
- 27 (pre-disaster* or post-disaster*).tw,kw,kf. (1215)
- 28 or/1-27 [Disaster] (543841)
- 29 disabled persons/ (42959)
- 30 disab*.tw,kw,kf. (239768)
- 31 amputees/ (3667)
- 32 mentally disabled persons/ or mentally ill persons/ (9708)
- 33 Visually Impaired Persons/ (2507)
- 34 chronic disease/ or multiple chronic conditions/ (267324)
- 35 rare diseases/ (11825)
- 36 convalescence/ or critical illness/ (34931)
- 37 Catastrophic Illness/ (1055)
- 38 (chronic disease* or chronic health or multiple morbid* or chronic comorbid*).tw,kw,kf. (81736)
- 39 *Vulnerable Populations/ (5141)
- 40 (Life adj3 (limit* or threaten*)).mp. (101162)
- 41 (complex* adj3 health).tw,kw,kf. (6367)
- 42 (complex* adj4 (medical* or needs or problem* or condition* or patient*)).tw,kw,kf. (68223)
- 43 (medical* adj3 fragil*).mp. (317)
- 44 Palliative Care/ (55783)
- 45 long term illness*.mp. (774)

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- 46 Neoplasms/ (436231)
- 47 Cystic Fibrosis/ (36115)
- 48 Cerebral Palsy/ (21145)
- 49 Neuromuscular Diseases/ (10369)
- 50 heart diseases/ (70719)
- 51 Dependent Ambulation/ (195)
- 52 parenteral nutrition, home/ (1124)
- 53 Parenteral Nutrition, Home Total/ (194)
- 54 Hemodialysis, Home/ (1986)
- 55 Home Infusion Therapy/ (694)
- 56 Ventilators, Mechanical/ (9040)
- 57 Tracheostomy/ (7812)
- 58 (Home* adj5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral)).tw,kw,kf. (6740)
- 59 (feed* adj3 tube*).mp. (8707)
- 60 (home adj3 medical device*).mp. (61)
- 61 ((Ventilator* or Technolog*) adj3 (assist* or depend*)).tw,kw,kf. (19687)
- 62 (special adj3 needs).mp. (7718)
- 63 exp Mental Disorders/nu [Nursing] (22157)
- 64 or/29-63 [Disabled persons] (1469488)
- 65 28 and 64 (23688)
- 66 infant/ or infant, newborn/ or infant, low birth weight/ or infant, postmature/ or infant, premature/ or infant, extremely premature/ (1159825)
- 67 child/ or child, preschool/ or children/ (1951987)
- 68 adolescent/ (2075740)
- 69 (Infan* or newborn* or new-born* or neonat* or baby* or babies or toddler* or minors* or boy or boys or boyhood or girl* or kid or kids or child* or preschool* or schoolchild* or school child or preadolescen* or adolescen* or juvenil* or youth* or teen* or

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under*age* or pubescen* or prepuberty* or puberty* or prepubescen* or
puber*).tw,kw,kf. (2460164)

70 Pediatrics/ (55105)

71 Pediatric Nursing/ (13579)

72 (pediatr* or paediatr*).tw,kw,kf. (391183)

73 or/66-72 [Children] (4453853)

74 and/28,64,73 (5380)

75 Disabled Children/ (6471)

76 pe?diatric* cancer*.mp. (4150)

77 childhood cancer*.mp. (9064)

78 CSHCN.mp. (447)

79 or/75-78 (19036)

80 and/28,79 (226)

81 Information Dissemination/mt [Methods] (5260)

82 Needs Assessment/og [Organization & Administration] (3233)

83 Relief Work/og [Organization & Administration] (1384)

84 Health Services Accessibility/og [Organization &
Administration] (7256)

85 "Delivery of Health Care"/og [Organization & Administration]
(21839)

86 Risk Assessment/ (278251)

87 Disaster Planning/og [Organization & Administration] (4673)

88 postdisaster*.mp. (514)

89 (disaster* adj4 (respons* or recover* or prepar*)).tw,kw,kf.
(5636)

90 "Health Services Needs and Demand"/mt, og [Methods,
Organization & Administration] (2131)

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- 91 Disaster Planning/mt, og [Methods, Organization & Administration] (6441)
- 92 Home Care Services/og [Organization & Administration] (7060)
- 93 Child Health Services/og [Organization & Administration] (5454)
- 94 Hospitals, Pediatric/og [Organization & Administration] (1627)
- 95 Emergency Medical Services/og [Organization & Administration] (8340)
- 96 *Health Resources/sd [Supply & Distribution] (1291)
- 97 Patient-Centered Care/og [Organization & Administration] (5506)
- 98 Social Media/ (9576)
- 99 social media*.tw,kw,kf. (15256)
- 100 facebook.mp. (4221)
- 101 virtual.mp. (67270)
- 102 twitter.mp. (3872)
- 103 Telemedicine/mt, og [Methods, Organization & Administration] (11929)
- 104 Telerehabilitation/mt, og [Methods, Organization & Administration] (300)
- 105 digital medicine.mp. (275)
- 106 digital health.mp. (2810)
- 107 virtual rehabilitation.mp. (150)
- 108 telehealth.mp. (6952)
- 109 (service* adj3 redesign*).mp. (464)
- 110 video.mp. (146601)
- 111 Remote Consultation/ (5090)
- 112 ((remote* or Virtual*) adj4 care).tw,kw,kf. (2864)
- 113 (care adj4 coordinat*).mp. (12463)
- 114 or/81-113 [Communication & Support] (610027)
- 115 og.fs. [Organization & Administration] (492658)
- 116 28 and 64 and 73 and (114 or 115) (714)

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117 28 and 79 and (114 or 115) (54)
118 116 or 117 (726)
119 limit 118 to yr="1995 -Current" (696)
120 limit 119 to english language (677)
121 remove duplicates from 120 (675)
122 comment/ or letter/ or news/ (1747518)
123 121 not 122 (658)

124 limit 123 to (systematic reviews pre 2019 or systematic reviews) (34)
125 limit 123 to "review articles" (120)
126 or/124-125 [Reviews] (141)
127 123 not 126 (517)

128 Caregivers/ (38902)
129 Family/ (77740)
130 parents/ or fathers/ or mothers/ or single parent/ (116305)
131 or/128-130 (219536)

132 28 and 114 and 73 and 131 (244)
133 limit 132 to yr="1995 -Current" (236)
134 limit 133 to english language (232)
135 comment/ or letter/ or news/ (1747518)
136 134 not 135 (225)
137 136 not 123 (181)

138 limit 137 to (systematic reviews pre 2019 or systematic reviews) (3)
139 limit 137 to "review articles" (17)
140 138 or 139 (19)
141 137 not 140 [Remaining] (162)

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CINAHL Search – Disaster CIN1

Date: March 23, 2021

#	Query	Results
	Limit to Academic Journals	389
S113	S110 AND S111 Limiters - Exclude MEDLINE records	431
	Limit to Academic Journals	985
S112	S110 AND S111	1,049
S111	LA English	7,571,853
S110	S108 AND S109	1,058
S109	PY 1995-2021	7,227,776
S108	S103 OR S107	1,076
S107	S24 AND S52 AND S60 AND S100 AND S106	70
S106	S104 OR S105	126,033
S105	(MH "Mothers+") OR (MH "Fathers") OR (MH "Parents")	91,826
S104	(MH "Caregivers")	36,890
S103	S101 OR S102	1,076
S102	S24 AND S68 AND 100	1
S101	S24 AND S52 AND S60 AND S100	1,076
S100	S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99	516,046
S99	TI (care N4 coordinat*) OR AB (care N4 coordinat*)	9,898
S98	(TI ((remote* or Virtual*) N4 care)) OR (AB ((remote* or Virtual*) N4 care))	1,954

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S97	TI video OR AB video	34,379
S96	TI (service* N3 redesign*) OR AB (service* N3 redesign*)	468
S95	TI telehealth OR AB telehealth	4,735
S94	TI virtual rehabilitation OR AB virtual rehabilitation	469
S93	TI digital health OR AB digital health	2,299
S92	TI digital medicine OR AB digital medicine	622
S91	(TI (social media* or twitter or facebook)) OR ((social media* or twitter or facebook))	28,848
S90	(MH "Remote Consultation") OR (MH "Telerehabilitation") OR (MH "Telenursing") OR (MH "Telepsychiatry") OR (MH "Teleradiology") OR (MH "Telepathology") OR (MH "Telemedicine") OR (MH "Telehealth")	27,251
S89	(MH "Social Media") OR (MH "Facebook") OR (MH "Twitter")	16,901
S88	(MH "Patient Centered Care") OR (MH "Continuity of Patient Care") OR (MH "Patient Care") OR (MH "Patient Education/MT/OG") OR (MH "Health Education/MT") OR (MH "Preventive Health Care/MT/PC")	95,628
S87	(MH "Health Resource Allocation/MT") OR (MH "Health Resource Utilization/MT")	371
S86	(MH "Emergency Medical Service Communication Systems") OR (MH "Emergency Service Information Systems") OR (MH "Education, Emergency Medical Services") OR (MH "Emergency Medical Services+")	109,187
S85	(MH "Hospitals, Pediatric)	9,925
S84	(MH "Health Services for Persons with Disabilities/MT/OG") OR (MH "Community Health Services") OR (MH "Community Health Nursing+") OR (MH "Community Mental Health Services+") OR (MH "Community Networks") OR (MH "Family Services") OR (MH "Rehabilitation, Community-Based") OR (MH "Maternal	105,603

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	Health Services+") OR (MH "Health Services, Indigenous")	
S83	(MH "Child Health Services/MT/OG")	100
S82	(MH "Home Health Care+/OG/MT")	1,154
S81	(MH "Disaster Planning+/MT/PC")	1,066
S80	(MH "Health Services Needs and Demand+/MT")	5
S79	(TI (disaster* N4 (respons* or recover* or prepar*))) OR (AB (disaster* N4 (respons* or recover* or prepar*)))	3,703
S78	TI postdisaster* OR AB postdisaster*	261
S77	(MH "Medical Countermeasures") OR (MH "Disaster Planning+/OG/MT") OR (MH "Mass Casualty Training")	1,487
S76	(MH "Risk Assessment")	113,420
S75	(MH "Health Services Accessibility/MT") OR (MH "Health Care Delivery/MT")	5,548
S74	(MH "Humanitarian Aid+/OG")	48
S73	(MH "Needs Assessment/OG")	2,414
S72	(MH "Needs Assessment/OG")	2,414
S71	(MH "Health Information Networks/OG/MT") OR (MH "Home Health Care Information Systems/OG")	12
S70	(MH "Selective Dissemination of Information/OG/MT")	3
S69	S24 AND S68	283
S68	S62 OR S63 OR S64 OR S65 OR S66 OR S67	26,985
S67	TI CSHCN OR AB CSHCN	323
S66	TI childhood cancer* OR AB childhood cancer*	4,690
S65	(TI (pediatric* cancer* OR peadiatric cancer*)) OR (AB (pediatric* cancer* OR peadiatric cancer*))	2,655

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S64	(MH "Childhood Neoplasms")	4,967
S63	(MH "Parents of Disabled Children")	4,552
S62	(MH "Child, Medically Fragile") OR (MH "Child, Disabled")	13,506
S61	S24 AND S52 AND S60	5,101
S60	S54 OR S55 OR S56 OR S57 OR S58 OR S59	1,297,957
S59	(TI (pediatr* or paediatr*)) OR (AB (pediatr* or paediatr*))	147,946
S58	(MH "Maternal-Child Nursing") OR (MH "Pediatric Nursing+")	24,625
S57	(MH "Pediatrics+")	21,856
S56	TI ((Infan* or newborn* or new-born* or neonat* or baby* or babies or toddler* or minors* or boy or boys or boyhood or girl* or kid or kids or child* or preschool* or schoolchild* or school child or preadolescen* or adolescen* or juvenil* or youth* or teen* or under*age* or pubescen* or prepuberty* or puberty* or prepubescen* or puber*)) OR AB ((Infan* or newborn* or new-born* or neonat* or baby* or babies or toddler* or minors* or boy or boys or boyhood or girl* or kid or kids or child* or preschool* or schoolchild* or school child or preadolescen* or adolescen* or juvenil* or youth* or teen* or under*age* or pubescen* or prepuberty* or puberty* or prepubescen* or puber*))	815,090
S55	(MH "Adolescence") OR (MH "Adolescent, Hospitalized")	547,297
S54	(MH "Infant, Premature") OR (MH "Infant, Postmature") OR (MH "Infant, Low Birth Weight+") OR (MH "Infant, High Risk") OR (MH "Infant, Drug-Exposed") OR (MH "Infant+") OR (MH "Child+") OR (MH "Infant, Hospitalized") OR (MH "Infant, Newborn+")	692,258
S53	S24 AND S52	21,697
S52	S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR	1,319,910

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	S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51	
S51	(MH "Mental Disorders+")	590,814
S50	TI (special N3 needs) OR AB (special N3 needs)	7,814
S49	(TI ((Ventilator* or Technolog*) N3 (assist* or depend*))) OR (AB ((Ventilator* or Technolog*) N3 (assist* or depend*)))	8,969
S48	TI (home N3 medical device*) OR AB (home N3 medical device*)	48
S47	TI (feed* N3 tube*) OR AB (feed* N3 tube*)	3,972
S46	(TI (Home* N5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral))) OR (AB (Home* N5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral)))	3,224
S45	(MH "Tracheostomy")	4,586
S44	(MH "Ventilators, Mechanical")	3,101
S43	(MH "Home Intravenous Therapy")	1,541
S42	(MH "Heart Diseases+")	291,316
S41	(MH "Neuromuscular Diseases")	2,370
S40	(MH "Cerebral Palsy")	12,596
S39	(MH "Cystic Fibrosis")	8,154
S38	(MH "Neoplasms")	84,895
S37	TI long term illness* OR AB long term illness*	1,301
S36	(MH "Palliative Care")	37,556
S35	TI medical* N3 fragil* OR AB medical* N3 fragil*	322
S34	TI ((complex* N4 (medical* or needs or problem* or condition* or patient*))) OR AB ((complex* N4	26,210

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	(medical* or needs or problem* or condition* or patient*)))	
S33	TI complex* N3 health OR AB complex* N3 health	5,490
S32	TI ((Life N3 (limit* or threaten*))) OR AB ((Life N3 (limit* or threaten*)))	26,724
S31	(MM "Special Populations")	3,032
S30	TI (chronic disease* or chronic health or multiple morbid* or chronic comorbid*) OR AB (chronic disease* or chronic health or multiple morbid* or chronic comorbid*)	94,231
S29	(MH "Recovery")	34,344
S28	(MH "Rare Diseases")	1,631
S27	(MH "Critical Illness") OR (MH "Catastrophic Illness") OR (MH "Chronic Disease+")	80,786
S26	TI disab* OR AB disab*	126,291
S25	(MH "Disabled") OR (MH "Amputees") OR (MH "Mentally Disabled Persons")	44,601
S24	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23	161,400
S23	TI (predisaster* or disaster* or postdisaster*) OR AB (predisaster* or disaster* or postdisaster*)	14,009
S22	TI (coronavirus* or SARS* or COVID*) OR AB (coronavirus* or SARS* or COVID*)	42,528
S21	(MH "Coronavirus Infections") OR (MH "COVID-19") OR (MH "Middle East Respiratory Syndrome") OR (MH "Severe Acute Respiratory Syndrome")	25,823
S20	TI (((natural or health) N5 catastrophe*)) OR (((natural or health) N5 catastrophe*))	122

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S19	TI (((Health* or infecti* or disease*) N5 outbreak*)) OR AB (((Health* or infecti* or disease*) N5 outbreak*))	6,898
S18	MH "Hemorrhagic Fevers, Viral+" AND outbreak*	2,601
S17	TI ((national or global or community) N5 (emerg* or outbreak*)) OR AB ((national or global or community) N5 (emerg* or outbreak*))	7,990
S16	TI evacuat* OR AB evacuat*	4,521
S15	(MH "Emergencies")	10,631
S14	TI (epidemic* or pandemic*) OR AB (epidemic* or pandemic*)	49,991
S13	TI infectious N5 disease transmission OR AB infectious N5 disease transmission	398
S12	(MH "Disease Transmission, Horizontal")	955
S11	(MH "Disease Outbreaks+")	40,949
S10	TI ((chemical or biological or radiological or nuclear) N3 (warfare or incident* or accident*)) OR AB ((chemical or biological or radiological or nuclear) N3 (warfare or incident* or accident*))	1,090
S9	TI CBRN OR AB CBRN	73
S8	TI (terrorism* or bioterrorism* or terrorist*) OR AB (terrorism* or bioterrorism* or terrorist*)	4,239
S7	(MH "Terrorism")	6,476
S6	TI nuclear N5 accident* OR AB nuclear N5 accident*	319
S5	(MH "Chemical Hazard Release") OR (MH "Biohazard Release")	319
S4	TI (avalanche* or cyclone* or drought* or earthquake* or flood* or landslide* or tidal wave* or tornado* or wildfire* or bushfire* or tsunami* or hurricane* or volcan* or explosion* or bushfire*) OR AB (avalanche* or cyclone* or drought* or earthquake* or flood* or landslide* or tidal wave* or tornado* or wildfire* or	13,128

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	bushfire* or tsunami* or hurricane* or volcan* or explosion* or bushfire*)	
S3	(MH "Fires+") OR (MH "Wildfires")	5,480
S2	(MH "Natural Disasters")	12,067
S1	(MH "Disasters") OR (MH "Emergency Evacuation") OR (MH "Mass Casualty Incidents")	9,778

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Summer 2020

Search strategies:

Ovid Medline

1. adolescent/ or child/ or child, preschool/ or infant/ or infant, newborn/
2. (infant or baby or babies or toddler* or preschool* or child or "child's" or children* or childhood or boy or boys or boyhood or girl or girls or girlhood or adolescen* or preadolescenc* or kid or kids or prepuberty* or puberty* or prepubescen* or puber* or pubescen* or teen* or youth*).ti,ab.
3. Pediatrics/
4. Pediatric Nursing/
5. (pediatr* or paediatr*).ti,ab.
6. parents/ or fathers/ or mothers/ or single parent/
7. (parent* or parents).ti,ab.
8. Legal Guardians/
9. Minors/
10. (guardian* or parent or parents).ti,ab.
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. disabled persons/ or chronic disease/ or multiple chronic conditions/
13. (disab* or chronic disease* or chronic health or multiple morbidities).ti,ab.
14. (complex needs or complex health needs or complex health care needs or complex healthcare needs or complex medical needs or complex health conditions or complex medical conditions).ti,ab.
15. (medical complexity or medical complexities or medically complex or medical fragility or medically fragile).ti,ab.
16. chronic comorbid*.ti,ab.
17. persons with hearing impairments/ or hearing disorders/ or blindness/ or deaf-blind disorders/ or deafness/
18. (visual impair* or hearing impair* or deaf* or blind* or hard of hearing).ti,ab.
19. home care services/ or home health nursing/ or home nursing/ or home care services, hospital-based/ or home health aides/
20. ((home health or Home care) adj3 (agenc* or service* or provider* or nurse* or nursing or patient*)).ti,ab.

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21. parenteral nutrition/ or parenteral nutrition, total/ or hemodialysis, home/ or home care services, hospital-based/ or home infusion therapy/ or parenteral nutrition, home/ or parenteral nutrition, home total/ or ventilators, mechanical/ or tracheostomy/
22. (Home* adj5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral or tube feed*)).ti,ab.
23. pediatricians/
24. (pediatrician* or paediatrician*).ti,ab.
25. (technolog* adj3 (assist* or depend*)).ti,ab.
26. (home medical device* or special healthcare or special health care or special needs).ti,ab.
27. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. disabled children/
29. (cshcn or cshcns or cmc or cmcs or yshcn or yshcns).ti,ab.
30. 28 or 29
31. 11 and 27
32. 30 or 31
33. communication/ or health communication/ or information dissemination/
34. (communicat* or correspond* or information or contact or contacting or contacted or contacts).ti,ab.
35. patient education as topic/ or social media/
36. (texting or text messag* or SMS or app or apps or mobile application or Internet* or online).ti,ab.
37. ((disrupt* or recover* or reestablish* or resum* or restor* or access* or receipt) adj5 (service* or care or network* or system or systems)).ti,ab.
38. needs assessment/
39. (assess* adj2 needs).ti,ab.
40. 33 or 34 or 35 or 36 or 37 or 38 or 39
41. disasters/ or emergencies/ or mass casualty incidents/ or natural disasters/ or avalanches/ or cyclonic storms/ or droughts/ or earthquakes/ or floods/ or landslides/ or tidal waves/ or tornadoes/ or wildfires/
42. terrorism/ or bioterrorism/ or chemical terrorism/ or mass casualty incidents/ or september 11 terrorist attacks/
43. Fukushima nuclear accident/
44. epidemics/ or pandemics/

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45. (predisaster or postdisaster or disaster or disasters).ti,ab.

46. CBRN.ti,ab.

47. (bioterror* or terror* or evacuat* or epidemic or epidemics or pandemic or pandemics).ti,ab.

48. 41 or 42 or 43 or 44 or 45 or 46 or 47

49. disaster planning/

50. 48 or 49

51. 32 and 40 and 50

52. (coronavirus or coronaviruses or 2019-nCov or SARS-CoV-2 or nCOV or COVID).ti,ab.

53. 30 and 52

54. 53 or 51

CINAHL

S1 (MH "Adolescence+") OR (MH "Child+") OR (MH "Infant") OR (MH "Infant, Hospitalized") OR (MH "Infant, Newborn+")

S2 TI (infant or baby or babies or toddler* or preschool* or child or "child's" or children* or childhood or boy or boys or boyhood or girl or girls or girlhood or adolescen* or preadolescen* or kid or kids or prepuberty* or puberty* or prepubescen* or puber* or pubescen* or teen* or youth) OR AB (infant or baby or babies or toddler* or preschool* or child or "child's" or children* or childhood or boy or boys or boyhood or girl or girls or girlhood or adolescen* or preadolescen* or kid or kids or prepuberty* or puberty* or prepubescen* or puber* or pubescen* or teen* or youth)

S3 (MH "Pediatrics")

S4 (MH "Pediatric Nursing")

S5 TI (pediater* or paediatric*) OR AB (pediater* or paediatric*)

S6 (MH "Parents") OR (MH "Fathers") OR (MH "Mothers") OR (MH "Single Parent") OR (MH "Parents of Disabled Children")

S7 TI (parent or parents*) OR AB (parent or parents*)

S8 (MH "Guardianship, Legal")

S9 (MH "Minors (Legal)")

S10 TI (guardian* or parent or parents) OR AB (guardian* or parent or parents)

S11 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10

S12 (MH "Chronic Disease+")

S13 TI (disab* or chronic disease* or chronic health or multiple morbidities) OR AB (disab* or chronic disease* or chronic health or multiple morbidities)

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S14 TI (complex needs or complex health needs or complex health care needs or complex healthcare needs or complex medical needs or complex health conditions or complex medical conditions) OR AB (complex needs or complex health needs or complex health care needs or complex healthcare needs or complex medical needs or complex health conditions or complex medical conditions)

S15 TI (medical complexity or medical complexities or medically complex or medical fragility or medically fragile) OR AB (medical complexity or medical complexities or medically complex or medical fragility or medically fragile)

S16 TI chronic comorbid* OR AB chronic comorbid*

S17 (MH "Hearing Disorders+") OR (MH "Blindness+")

S18 TI (visual impair* or hearing impair* or deaf* or blind* or hard of hearing) OR AB (visual impair* or hearing impair* or deaf* or blind* or hard of hearing)

S19 (MH "Home Health Care+")

S20 TI ((home health or Home care) N3 (agenc* or service* or provider* or nurse* or nursing or patient*)) OR AB ((home health or Home care) N3 (agenc* or service* or provider* or nurse* or nursing or patient*))

S21 (MH "Parenteral Nutrition+") OR (MH "Ventilators, Mechanical") OR (MH "Respiratory Therapy+") OR (MH "Tracheostomy Care")

S22 TI (Home* N5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral or tube feed*)) OR AB (Home* N5 (ventilation or ventilator* or infusion* or hemodialysis or dialysis or parenteral or tube feed*))

S23 (MH "Pediatricians")

S24 TI (pediatrician* or paediatrician*) OR AB (pediatrician* or paediatrician*)

S25 TI (technolog* N3 (assist* or depend*)) OR AB (technolog* N3 (assist* or depend*))

S26 TI (home medical device* or special healthcare or special health care or special needs) OR AB (home medical device* or special healthcare or special health care or special needs)

S27 S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26

S28 (MH "Child, Disabled")

S29 TI (cshcn or cshcns or cmc or cmcs or yshcn or yshcns) OR AB (cshcn or cshcns or cmc or cmcs or yshcn or yshcns)

S30 S28 OR S29

S31 S11 AND S27

S32 S30 OR S31

S33 (MH "Communication")

S34 TI (communicat* or correspond* or information or contact or contacting or contacted or contacts) OR AB (communicat* or correspond* or information or contact or contacting or contacted or contacts)

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S35 (MH "Patient Education") OR (MH "Social Media+")

S36 TI (texting or text messag* or SMS or app or apps or mobile application or Internet* or online) OR AB (texting or text messag* or SMS or app or apps or mobile application or Internet* or online)

S37 TI ((disrupt* or recover* or reestablish* or resum* or restor* or access* or receipt) N5 (service* or care or network* or system or systems)) OR AB ((disrupt* or recover* or reestablish* or resum* or restor* or access* or receipt) N5 (service* or care or network* or system or systems))

S38 (MH "Needs Assessment")

S39 TI assess* N2 needs OR AB assess* N2 needs

S40 S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39

S41 (MH "Disasters") OR (MH "Emergency Evacuation") OR (MH "Fires") OR (MH "Wildfires") OR (MH "Mass Casualty Incidents") OR (MH "Natural Disasters")

S42 (MH "Terrorism") OR (MH "Bioterrorism")

S43 TI (september 11 OR fukushima nuclear OR avalanche* OR hurricane* OR drought OR droughts OR eathquake OR landslide OR tidal wave* OR tornado* OR wildfire* OR natural disaster*)

S44 TI (epidemic OR epidemics OR pandemic*) OR AB (epidemic OR epidemics OR pandemic*)

S45 TI (predisaster or postdisaster or disaster or disasters) OR AB (predisaster or postdisaster or disaster or disasters)

S46 TI CBRN OR AB CBRN

S 47 TI (bioterror* OR terror* OR evacuat*) OR AB (bioterror* OR terror* OR evacuat*)

S48 S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47

S49 MH "Disaster Planning"

S50 S48 OR S49

S51 S32 AND S40 AND S50

S52 TX coronavirus OR coronaviruses OR 2019-nCov OR SARS-CoV-2 OR nCOV OR COVID

S53 S30 AND S52

S54 S51 OR S53

Total results: 284

Grey literature

- Google Scholar ("Medical complexity" OR "medically complex" OR "medically fragile" OR "medical fragility" OR "special health care needs") AND (disaster OR epidemic OR pandemic)
 - NOTE: COVID not included as search term, as many article pages advertised COVID results, and this generated many irrelevant results
 - First 100 results reviewed

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- MedRxiv (“Medical complexity”; “medically complex”; “medically fragile”; “medical fragility”; “special health care needs”; CMC; CYSHCN; YSHCN)
 - No relevant results
- TRIP
 - First 100 results reviewed; no additional results found
- PEDro (“Medical complexity”; “medically complex”; “medically fragile”; “medical fragility”; “special health care needs”; CMC; CYSHCN; YSHCN)
- OAlster (“Medical complexity”; “medically complex”; “medically fragile”; “medical fragility”; “special health care needs”; CMC; CYSHCN; YSHCN)
- Google: (“Medical complexity” OR “medically complex” OR “medically fragile” OR “medical fragility” OR “special health care needs”) AND (disaster OR epidemic OR pandemic)
 - First 100 results reviewed