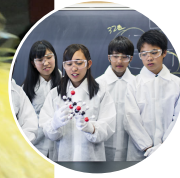


**The State of Pediatric Disaster Education:
A Comprehensive Review & Analysis Report
SECTION 11. CHILDREN AND YOUTH WITH DISABILITIES AND MEDICAL NEEDS**



Children
and Youth



With



Disabilities



and Medical



Needs

This section is part of a comprehensive review and analysis of current issues and trends in pediatric disaster education. The report explores current gaps and opportunities in pediatric disaster education. A Pediatric Disaster Education Concept of Operations is recommended to assure whole community inclusion of children in all phases of the disaster.

Eastern Great Lakes Pediatric Consortium for Disaster Response: Education Workgroup
June 2021

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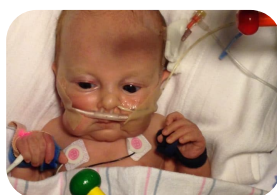
Children and Youth with Disabilities and Medical Needs

According to the [CDC](#), one in five U.S. children has a special health care need.¹ Children and Youth with Disabilities and Medical Needs (CYDMN) are children who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally."²

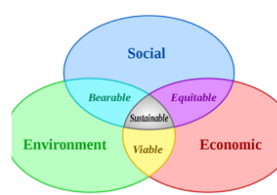
These children rely on the ability of their parents and caretakers to assure they have access to health care, medications, food, water, shelter, durable medical equipment and transportation in the event of a disaster. They face a multitude of challenges as part of routine care that are exacerbated when disaster strikes. A recent national statistical brief prepared by [Child Trends](#) reported CYDMN experience the following at higher rates than their peers.³



Family Poverty



Disparities in
Accessing a Medical
Home



Gaps in Economic
Resources



1 in 34 Have No
Insurance



Child Care Difficulties



Miss School & Repeat
Grades

In 2018, the [National Advisory Committee on Children and Disasters \(NACCD\)](#) stated that the care of children with disabilities (identified as children and youth with special health care needs [CYSHCN] in the report) were a high priority during disasters, but were subject to numerous gaps in provider- and community-level disaster readiness training.⁴ The report called for a whole-community educational campaign that not only emphasized basic preparedness but also taught parents and other providers (e.g. teachers, childcare staff, hospital staff, first responders, shelter workers, etc.) how to emotionally support children in a disaster and when they should seek assistance.

Three years later, in 2021, the Eastern Great Lakes Pediatric Consortium for Disaster Response (EGLPCDR), conducted a pediatric disaster competency survey. The findings indicate that health care providers—regardless of discipline—expect Emergency Department and hospital providers be “proficient” in the care of CYDMN, which were defined as Children with Functional and Access Needs (CFAN) in the survey.⁵

High expectations of competency are clearly a challenge, given that community hospital

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emergency care providers have little collective contact or experience with CYDMN. In addition, CYDMN families disproportionately rely on their pediatric regional center specialists for much of their routine care.⁶ The numerous disaster education gaps associated with CYDMN require further exploration in order to assess the state of disaster readiness education among CYDMN families and providers.

EGLPCDR Pediatric Disaster Competency Survey Results

Survey Results: ED/Hospital Systems and Resources Emergencies (N=226 Completed Surveys)

Core Disaster Operations	Emergency Care Providers	Surge Providers	Disaster Leadership	Support Provider
Diagnostic/Treatment	P	P	P	A
Surge Related	P	P	P	A
Identification/Tracking	P	P	P	A
Regionalization	A	A	P	A
Evacuation/Transport	P	P	P	A
Children (CFAN)	P	P	A	A
PH Orgs	P	A	P	A
Roles and Responsibilities	A	A	P	A

Chart Legend: A = Awareness; P = Proficient; CFAN = Children with Functional and Access Needs; PH Orgs = Public Health Organizations.

Exploring the Gaps in Current Disaster Education Resources for CYDMN

In January 2021, complex care subject matter experts and advisors from the EMSC/EIIC's Family Advisory Network were added to the Workgroup to assist in the effort to evaluate the current state of CYDMN disaster educational resources for families and providers.

A simple Google search approach to assess the scope of public, non-profit, and academic educational content available to communities. The findings are summarized in the chart below:



The search yielded a voluminous array of information. Yet, a deeper dive of the first 50 results

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for each search term revealed that most of the links consistently referred back to trusted sources such as Federal Emergency Management Agency (FEMA), the Red Cross, the Center for Disease Control and Prevention (CDC), and the AAP.

The group also reviewed unique content that was produced and curated by family and child disabilities advocates. This provided a rich source of practical, real-world lessons learned that often included peer testimonials; tips on community engagement; information about how to navigate services and deal with specific hazards using social media (i.e., Instagram, TikTok, Twitter); and online videos and recorded webinars available via YouTube.

Overall, individuals who are seeking information, guidance, or training about disaster readiness for families of CYDMN will experience the following:

- An overwhelming amount of information that is difficult to navigate.
- Broken resource links to materials, requiring additional online searches.
- Content that is clearly out-of-date or no longer supported.
- Lack of methods and frequency in evaluating the quality of training the materials.
- Lack of consistent content creation dates and updates.
- Lack of transparency about how often resources were viewed or accessed.
- Portal registration requirements that impede access to the content.
- Proprietary tools and resources that require purchase without the ability to preview them.

Provider CYDMN Disaster Education and Training Resources

Few trainings exist that target health care coalitions and cross-sector disciplines inclusive of CYDMN. The exception is the two-day [FEMA Mgt-439 Course](#): Pediatric Disaster Response and Emergency Preparedness. The course content covers CYDMN disaster planning and operational content, and draws on real world people and events with an emphasis on sheltering, durable equipment, power failures, and family preparedness. Attendees reported a 66.8% improvement in their occupational knowledge, skills, and activities in the area of CYDMN.⁷

In contrast just-in-time (JIT) provider educational content is focused on developing and troubleshooting hands-on clinical skills in the care of gastrostomies, feeding tubes, tracheostomies, and other medical devices that providers encounter in normal or disaster conditions.

The Workgroup SMEs identified, reviewed, and compiled 273 focused articles, publications, websites, templates (including toolkits), and multi-media training resources for CYDMN as suitable for JIT disaster education. Of these, 123 all-hazard and 150 COVID-19 disaster resources were compiled. Each resource was categorized by content quality, date created, medium used (e.g., video, webpage, template), target audience, level of training, length of time, and condition specificity (e.g., autism). As vetted materials were identified, they were published to the [EIIC Children and Youth with Special Health Care Needs Disaster Webpage](#) for

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use by other stakeholders.

Critical Gaps of CYDMN Family Disaster Readiness

Nothing teaches like real-world disasters and, in the midst of the COVID-19 pandemic, the nation also experienced the [February 2021 Texas](#) winter storm and subsequent devastating power failure.⁸ The Texas storm was a once-in-a-century severe weather incident that caused disaster conditions and resulted in the loss of power, water, and access to health services for a large portion of the state—including numerous CYDMN children. Colleagues at Texas Children’s reported that families with CYDMN used their hospital as a safe haven and were generally unaware of their family responsibility in ensuring disaster readiness for their child.

This incident illustrates that, when families are not disaster-ready, pediatric regional centers and community hospitals become the default safety net. This finding is supported by the results of a 2020 national survey of American families, which found that, although most families believe that they will be impacted by a natural disaster in the next 3-5 years, more than one-quarter ([27%](#)) have not taken *any* steps to prepare for such disasters.⁹ CYDMN families are part of this national statistic, despite the fact that they are at significantly higher risk for adverse outcomes compared to the general population.^{10 11}

As a result of this lesson learned, the need for JIT materials to serve these families became one of the project team’s key focuses. Workgroup efforts to this end began with an exploration of disaster preparedness content for CYDMN, including a review of trusted resources to identify best practices. Links to informational websites, podcasts, videos, checklists, and guidance prioritizing AFN families and children were identified, compiled, and reviewed. Resources were reviewed from trusted sources that included FEMA, the Red Cross, the AAP, the CDC, pediatric regional specialty centers, pediatric complex care clinics, and AFN advocacy groups such as [Family Voices](#) and [Complex Child](#).

A review of disaster readiness instructional videos on YouTube identified variations in quality, content delivery, ADA compliance, and viewing time. View counts and view rates by year (calculated as total views divided by number of years on YouTube) strongly suggest that the content has limited engagement, with only two videos dedicated to a CYDMN focus. Findings are summarized in the table below. (**Legend:** ENG: English. CC: Closed Captioned ASL: American Sign Language)

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Functional/Access Needs Preparedness	Source	Year Created	View Time	Number of Views ¹²	Views by year	ADA	Focus on CYDMN
Emergency Disaster Preparedness	FEMA/ Ad Council	2017	2 min	10,924	2,731	ENG CC Voice	No
Emergency Preparedness for Families of Children with Disabilities	Navigate Texas Life	2015	5 min	142	24	ENG CC Voice	Yes
Disaster Preparation for the Disabled Community of Washington	Washington State	2021	1 min	10	10	ENG Voice CC	No
County of Santa Cruz: Get 72 Hour Ready	FEMA	2013	5 min	24,834	3,104	ASL Voice	No
Emergency Preparedness in the Home	Mountain Star Health	2016	5 min	566	113	ENG Voice	No
How to Prepare for a Disaster	AAP	2020	30 sec	798	399	ENG Voice	No
American Red Cross Disaster Preparedness for People with Disabilities	Red Cross	2013	10 min	7,484	935	ENG Voice	No
Disability Inclusive Disaster Risk Reduction-Social Cause Video	YourVideoz	2016	3 min	715	143	ENG Voice	No
Emergency Preparedness for Families of Children with Special Health Care Needs	Family Voices Massachusetts	2017	31 min	280	70	ENG Voice	Yes
Emergency Preparedness for People with Disabilities	New Jersey Dept of Health	2016	<3 min	1,024	205	ENG Voice	No
Preparedness Tips for People with Disabilities	NWS New Mexico	2020	<4 min	77	77	ENG Voice CC	No
Disaster Readiness for People with Paralysis and Other Disabilities	World Institute on Disability	2019	13 min	403	200	ENG Voice	No
Family Emergency Preparedness Tools Instructional Video	NCMEC	2019	10 min	2223	1111	ENG Voice	No
How People With Disabilities Can Prepare for an Emergency 	Now This	2020	5 min	2034	2034	ENG ASL CC	No

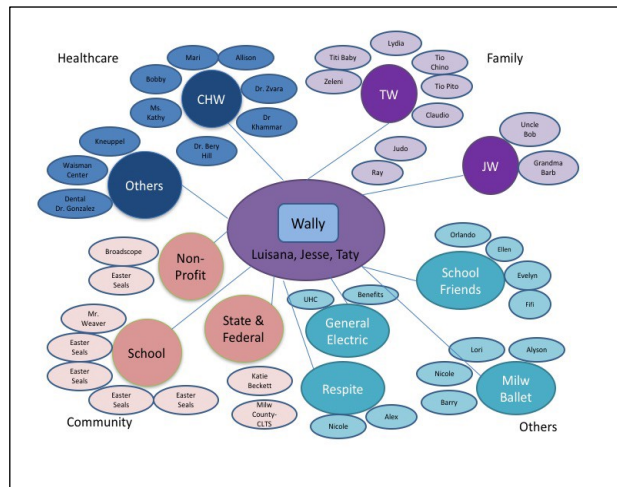
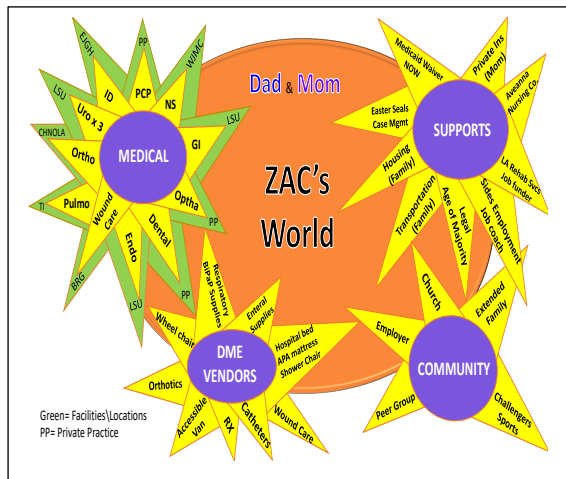
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Educational Gaps in Situation Awareness Associated with CYDMN

Emergency managers and health care coalitions may not be aware of how many CYDMN exist in their communities. One tool that is gaining traction to help providers understand the needs of CYDMN and their families is [Care Mapping](#) (see below for examples).¹³ Care mapping is used by families with disabled and complex medical needs children. It provides a comprehensive snapshot of a family's needs and is used by families and providers to coordinate complex care services. Care maps can be instrumental in helping the family anticipate what services are likely to be disrupted in disaster. Care mapping should be used by providers and families to anticipate and mitigate worst case scenarios if disruptions occur in needed specialty care, supply chain, support personnel, or community services.¹⁴

Care Mapping Examples



Educational Gaps Associated with Disability and Disaster Legislation

Disaster education and training of providers to meet the needs of the disabled community is strongly associated with numerous legislative mandates. Those mandates facilitate the inclusiveness in the [National Disaster Recovery Framework](#) and are fully integrated into FEMA's whole community guidance. While legislatively CYDMN are part of a broader disabled population and families with disabled children are benefit from of the rights and advantages conferred by disability legislation. Disability legislation creates the regulatory framework and jurisdictional to impose education and training requirements for local, regional, and state stakeholders who receive federal funds and assures accessible services across the disaster continuum. This legislation, which relies on informed advocates to operationalize, includes:

- The Individuals with Disabilities Education Act (IDEA), which makes free and appropriate public education to [eligible children with disabilities](#) throughout the nation and ensures special education and related services are provided to those children.

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- The [U.S. Department of Education’s Office for Civil Rights](#) (OCR), which provides additional resources of interest for individuals with disabilities and their families.
- The [Rehabilitation Act of 1973, Section 504](#), which is a federal law designed to protect the rights of individuals with disabilities from being excluded from any programs or activities that receive federal funds.
- Title II of the [Americans with Disabilities Act of 1990](#), which extends protection against discrimination to the full range of state and local government services, programs, and activities—including public schools—regardless of whether they receive any federal financial assistance.
- [2019 Pandemic and All-Hazards Preparedness and Advancing Innovation Act](#), which strengthens provisions for children and other at-risk populations during disasters.

Educational Gaps in Health Care Coalitions Associated with CYDMN

While this significant body of legislation sets the stage to support CYDMN’s inclusion in disaster readiness, the primary authority for AFN disaster readiness and training may sit with local Public Safety Office of Emergency Services (OES), rather than with regional health care coalitions. Gaps in collaboration and education between the regional OES departments and health care coalitions can impede situation awareness, information-sharing, and opportunities to conduct medical health preparedness exercises.

Health care coalitions benefit from education and training on the economic, educational, and community services that CYDMN receive outside of the hospital and health care system. These services include food assistance and in-home services supporting activities of daily living for all access and functional needs populations. The services help coalitions leverage partnerships with schools, regional disability centers, and local transport authorities.

Disaster preparedness, response, and recovery disproportionately relies on CYDMN caregivers to provide JIT education and training to disaster responders regarding their child’s special needs and serve as part of their own response community. Disaster readiness guidance generated from the AFN and CYDMN community has a strong emphasis on redundant back-up plans and networks of friends, caregivers, and services that can be at the ready to meet any hazard.

Examples of gaps in CYDMN disaster preparedness that could be mitigated with normalizing CYDMN disaster preparedness include: ¹⁵

- Inadequate or disrupted power supply for families with children with disabilities, especially those who are technologically dependent seeking shelter or power at local emergency departments and hospitals.
- Families without backup power for medical devices, infusion pumps, or ventilators.

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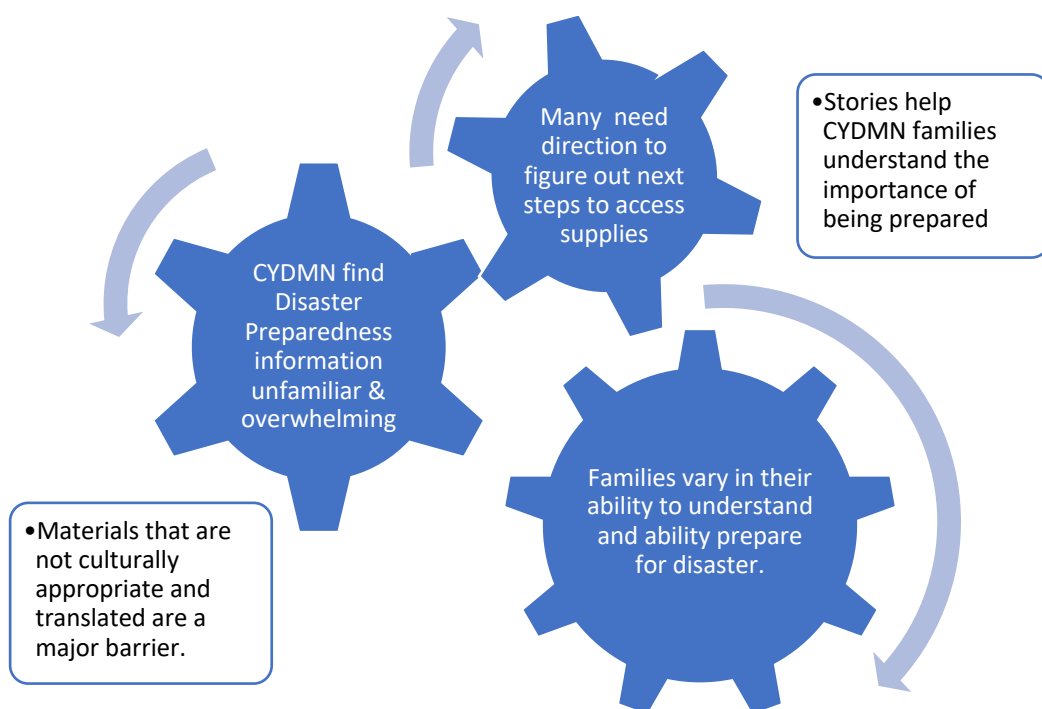
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- School bus accidents involving children with disabilities who lack identification or medical alert bracelets, delaying identification of victims and complicating reunification.
- CYDMN families who are unable to evacuate due to lack of accessible transportation.
- Non-accessible shelters during disaster, resulting in delays in the ability to evacuate.
- CYDMN without extra supplies (e.g., gastrostomy or tracheostomy).
- Youth with wheelchairs who become stranded on upper floors without evacuation assistance.
- Shelters without quiet rooms or spaces for children who are subject to overstimulation and high stress environments (e.g., autism).

Lessons Learned from CYDMN Disaster Preparedness Interventions

In June, 2015 the AAP and Family Voices conducted a pilot-test of educational handouts, entitled: *Starting the Preparedness Conversation with Pediatricians and Families*. This educational pilot program created handouts designed to be used by pediatricians and CYDMN families to promote disaster preparedness discussions and information-sharing. The pilot revealed the following important findings:¹⁶

Starting the Preparedness Conversation with Pediatricians and Families



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Best Practices in CYDMN Disaster Readiness

Providing materials in formats that are accessible to all CYDMN families requires that the materials are not only ADA compliant but reflect the cultural diversity of the disabled community. A review of established resources for disabled community and CYDMN families from FEMA, the Red Cross, AAP, and the CDC found that most materials for CYDMN families were primarily in English, and rarely translated in other languages (e.g., Spanish). While some websites Most instructional videos were created between 2013 and 2020, and a number of them are not fully consistent with principles of [Universal Design](#) or the American Disabilities Act (ADA), which promote the use of Closed Captioning (CC), and American Sign Language (ASL). This is important because:

- “Universal Design” is recognized by the WHO as the design of products, environments, programs, and services so they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design; it does not exclude assistive devices for particular groups of persons with disabilities where this is needed.¹⁷
- American Sign Language is known to be vital, especially for children who are medically fragile and non-verbal—as told in newsletters and blogs.¹⁸
- Closed Captioning is the process of displaying text on a television, video screen, or other visual display in order to provide additional or interpretive information through text.

Storytelling is a powerful educational strategy for engaging families in disaster readiness.¹⁹ The CYDMN advocacy group [Complex Child](#) created a number of story-telling blogs using the Family-to-Family Approach; in this approach, peer parents create care tips for emergencies or disrupted services. In contrast, materials prepared by health care providers and organizations may not include examples of real-world experience or lessons learned from AFN peers. The Family-to-Family approach is highly valued among AFN and CYDMN groups and aligns with [FEMA’s three disaster ready themes](#): 1) Being Informed; 2) Building a kit; and 3) Making a plan.

Finally, CYDMN families benefit from mentoring; assistance with problem-solving; and consistent, gentle, non-intimidating messaging—especially when language barriers, time, and economic constraints exist.^{20 21}

Disaster Ready Web-based Resources for CYDMN Families:

The following is an annotated list of resources that reflect the breadth of information, guidance and research in this area. Substantial contributions have been made to inform families with disabled or medically complex children and the health care providers of disaster impacts to this vulnerable community. These served as part of the source material for the workgroup’s “Be Ready...Tips for Families of Children and Youth with Disabilities and Medical Needs.”

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Annotated List of Disaster Ready Web-based Resources for CYDMN Families
<p>Special Needs Alliance Emphasis on establishing a personal support network; completing a personal risk assessment. Preparing a disaster supply kit. Enrolling in a special needs registry and performing advance financial planning.</p>
<p>Natural Hazards Center Research Counts: Children and Disasters Special Collections A series of original briefs, toolkits and resources from experts in public health, medicine, psychology, sociology, urban planning and other disciplines. The brief “Evacuating Under Fire” provides a series of links to toolkits covering the ACEP Emergency information Form for Children with Special Health Care Needs CDC Checklist for Emergency Kit for CYDMN and the Rand Getting to Outcomes Interactive Tool : A user friendly process for comprehensive planning, implementation guidance and evaluation of programs and community initiatives.</p>
<p>CDC: Safety and Children with Disabilities Emergency Preparedness This website provides the essential CYDMN guidance in line with FEMA’s Get a Kit. Make A Plan. Be Informed. The site has a link that translates the information into Spanish and refers to other CDC linked resources as well as Ready.gov</p>
<p>Care Connection for Children Readiness focuses on guidance to Think Ahead: Types of Emergencies and Disasters, Resources. Emergency Planning and Preparation: Emergency Supply Kits, Develop an emergency plan for your child, family and neighborhood. Response and Recovery: Evacuation, What to Do When Disaster Strikes, Tips to Help Families Support Their Children Disaster Checklist, Emergency Information List and Special Equipment List.</p>
<p>AAP Children and Disasters: Children and Youth with Special Needs Written Plans. Disaster Supply Kit (Medications, Power Supply, Food and Supplies, Transportation. Coping and Adjustment. Additional guidance and links to other vetted resources. (The AAP is in the process of updating the organizational website; hence, no link is available at this time.)</p>
<p>Disaster Preparedness Toolkit for Families with Children with Special Health Care Needs Drexel University School of Public Health. Separate Checklists for Families with Physical Disabilities, Intellectual or Developmental Disabilities, Hearing or Vision Loss, Emergency Evacuation Shelter FAQ, Local Resource Guide, Checklist of Pediatric Medical Practices.</p>
<p>State of Alaska Disaster Preparedness for families of children and youth with special health care needs. This 24-page document, in English promotes thinking ahead, planning and preparation, response and recovery, resources for families with templates. The toolkit recommends CYDMN families prepare to be self-supporting for up to 10 days and includes checklists and recommends a number of web resources.</p>
<p>Ready Now! An Emergency Preparedness Tool Kit for People with Disabilities. This 156 page "Ready Now!" toolkit from the Oregon Office on Disability and Health is for people with disabilities and emphasizes independence, allowing each person to address his or her specific needs. 10 step emergency preparedness, what emergencies to expect, personal ability self-assessment, how to develop a personal support network, emergency contact list, emergency papers, tips for specific disabilities, should I stay, or should I go, Go-Kits and 72-hour supply, service animals, Emergency evacuation plans and summary checklist.</p>
<p>Preparing for Disaster for People with Disabilities and other Special Needs. This 20-page</p>

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booklet from FEMA and the American Red Cross helps people with disabilities prepare for all kinds of emergencies. Why Prepare. Create a Personal Support Network. Complete a Personal Assessment: Daily Living, Getting Around. Evacuation, Get informed, Make a Plan, Action Checklist, Assemble Disaster Supply Kit.
Surviving a Power Outage with Complex Medical Needs Complex Child Tips and recommendations from CYDMN families to families with CYDMN covering challenges associated with power outages and how to pre-plan and mitigate these events.
EIIIC: Children and Youth with Special Health Care Needs An extensive compilation of CYDMN education and training resources for policy makers, health care provider, emergency managers and families covering both clinical conditions and disaster information from vetted resources created as part of the EGLPCDR Education Workgroup.
Oregon Family to Family Health Information Center Tip Sheets and Toolkits This site offers comprehensive resource toolkits in pdf formats for CYDMN families covering all aspects of day-to-day and disaster readiness by families for families. Special Education Toolkits, Grandparent toolkits, Social and Emotional Health and Condition specific toolkits with robust resources from Autism Speaks, United Cerebral Palsy, Diabetes, Downs Syndrome, Epilepsy, Tube Feedings and Safety plans.
American Red Cross Disaster Safety for People with Disabilities. The site uses the “Be Red Cross Ready” national, standardized program to help people understand, prepare for and respond appropriately to disaster and fire. The website offers extensive online guidance with an emphasis on planning ahead, having a back-up plan and an evacuation plan. Videos on the site are closed caption and ASL compliant. The Red Cross Free emergency app is promoted on the site.
Disaster Planning for Children & Youth with Special Health Care Needs Website sponsored by Family Network on Disabilities guidance on need to plan, CYDMN checklist and care planning.

The “Be Ready - Tips for Families of CYDMN” Project Design

Informed by the review of best practices, lessons learned, and available disaster preparedness materials, the Workgroup conducted a brainstorming session to inform content design. By the end of the brainstorming session, the team had agreed on the development of a deployable toolkit for on-boarding CYDMN families to disaster readiness. The toolkit features will include:

- Flexible content for use across community, public safety, health care, and emergency management sectors.
- Alignment with best practices and disaster messaging used by FEMA, the Red Cross, the CDC, the AAP, AFN Advocacy & Family Advisory Groups.
- Content format that is compatible for use in a variety of settings such as classrooms, virtual instruction, self-study, conference presentations, disaster skills and exercise opportunities, and patient teaching in medical offices.
- Materials that are accessible, downloadable, web-based, open-source, and offered as

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no cost materials and just-in-time guidance.

- Short video length (no more than 5-15 minutes) suitable for JIT deployment.
- Companion infographics that cover all aspects of disaster readiness and can be used separately or as a package.
- ADA-compliant video content and formats.
- Offered in multiple languages.

The final work product is in development. It will consist of a six-minute video aligned with the best practices described above. The video content and companion infographics were vetted by Workgroup members, CYDMN subject matter experts, and EMSC/EIIC family advisory members. Next steps include modifying the training materials to be ADA compliant and translating in multiple languages. The Workgroup is creating a “Be Ready: Tips for Families of Children with Special Healthcare Needs” toolkit dissemination plan with methods to measure impact.



Summary & Recommendations

Educational content, resources and training opportunities exist to support CYDMN disaster-ready engagement. Nonetheless, CYDMN families and their providers experience numerous systemic education, access and supply chain barriers that are critical to family disaster readiness.

Because of the void in emergency preparedness education and support for CYDMN and their families, it is critical for disaster readiness to be normalized and expand to ensure that families are informed, educated, and feel confident in responding to and caring for their CYDMN during a disaster.

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The following recommendations are targeted in addressing the systemic and structural barriers associated with disaster readiness for CYDMN.

- Normalize disaster readiness in the CYDMN population by engaging health care coalitions and pediatric regional centers to create processes to successfully orient families to the basic principles of disaster readiness.
- Fully integrate disaster readiness for CYDMN as part of complex care coordination standards.
- Routinely engage CYDMN family representatives in disaster readiness exercises and planning.
- Include disaster readiness as part of routine anticipatory guidance and the use of [low-cost educational disaster supply starter](#) kits across disciplines to bridge the disaster readiness gaps experienced by CYDMN families.²²
- Ensure that disaster ready education materials for AFN are compliant with ADA requirements (i.e., voice, sound, closed captioning) and available in multiple languages.
- Include emergency and disaster readiness in the new [National Care Coordination Standards for Children and Youth with Special Health Care Needs](#). Disaster readiness for CYDMN relies on a strong foundation of care coordination. In a national survey of families of children with special needs responded, over 72% required care coordination assistance under routine normal conditions.²³
- Stakeholders and policy leaders should create reliable systems that reduce barriers to disaster readiness for the CYDMN community aligned with Pediatric Disaster Education Concept of Operations.
- Care mapping should be used as a tool for situational awareness to help families mitigate disruptions in essential services anticipated in a disaster.
- Stakeholders should be engaged in the dissemination of the “Be Ready: Tips for Families of Children with Special Healthcare Needs” toolkit with methods to measure impact.

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The State of Pediatric Disaster Education: A Comprehensive Review & Analysis Report
CHILDREN AND YOUTH WITH DISABILITIES AND MEDICAL NEEDS

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