
Abstract:

There is an ever-growing population of children with special health care needs ranging from children with pervasive developmental disorders to technology-dependent children. The prehospital provider, local emergency medical services agencies, and the state and federal entities involved in the prehospital care of children require focused programs to ensure safe and effective care and transport of these children. This article discusses the key factors involved in the prehospital care of these children including the use of registries to identify these patients in the community, the use of caregivers and emergency information forms as resources, and the existence of specialized training programs to educate prehospital providers about the special care needs of this population. Additional discussion includes the importance of medical homes for these children and special considerations regarding their transport. Finally, we will discuss the issues that arise in this community during a disaster and show how all the previously discussed aspects of care can be integrated into a comprehensive disaster plan.

Keywords:

Children with special health care needs; prehospital; technology dependent; disaster preparedness; emergency information forms

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The Prehospital Care of Children With Special Health Care Needs

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Children with special health care needs (CSHCN) comprise a growing group of children that use a significant proportion of the health care resources within their communities. As medical technology and our understanding of certain chronic conditions improve, these children are living longer and more fulfilling lives at home with their families. However, they do present day-to-day challenges for their families and can present a unique set of challenges to the prehospital provider who is frequently unfamiliar with their medical issues and with the medical technology that accompanies them.

Children with special health care needs are defined as those children with needs that are long term, lasting more than 6 months, and are more significant than that of the general population. Per a data query from the Child and Adolescent Health Measurement Initiative, the prevalence of this group is on the rise, with national estimates rising from 12.8% in 2001 to 15.1% in 2009 to 2010.¹ Some have expanded the definition to include not only children who are technology dependent but also those children with significant behavioral and developmental disorders, such as autism, in many cases, making this group more difficult to identify.²

Medically complex children are not just increasing in numbers. As they live longer, they also use a greater number of hospital days and charges when compared with children without complex medical conditions. One study showed that this group had an increase in hospitalizations of more than 19% from 2004 to 2009 and accounted for 81.7% of the hospital days for all children

admitted at 28 children's hospitals across the US.³ Another study reviewing hospital discharges from a large pediatric tertiary care center found that 41% of all patients sent home were technology dependent. The most common technologies used in this population were gastrostomy or jejunostomy tubes (10%), central venous catheters (7%), medication nebulizers (7%), ventriculoperitoneal cerebrospinal fluid shunts (2%), or tracheostomies (1%).⁴ Despite the broader definition of CSHCN as discussed above, the scope of this article will focus more specifically on a subset of this group and more closely examine the prehospital issues for those children with more significant medical complexity and technology dependence.

In 1997, the Emergency Medical Services (EMS) for Children program convened a special task force designed to examine the emergency care needs for this population.⁵ The subsequent literature relevant to the prehospital care of this unique patient population revolves around several specific topics that we will address. First, the identification of these patients in the community is a challenge for prehospital providers. Attempts to identify the location of these children through specific registries have been attempted with varying degrees of success. Prehospital providers require additional education on the unique care and transport needs of these patients and often use primary caregivers as a resource. There is new information on the advent of an emergency information form (EIF) to help provide additional information to the prehospital provider. Lastly, we will review the relevant literature that addresses the importance of a medical home and preparedness for eventual disasters.

BENEFIT AND SUSTAINABILITY OF STATE OR COUNTY REGISTRIES

Early attempts at producing a registry of CSHCN were met with various degrees of success. In the UK, such information is needed for the planning purposes of the various District Health Authorities. One community, the West Lambeth Health Authority, attempted to change the way these data were both collected and stored in the early 1980s.⁶ They identified that the current system was failing to truly identify children requiring specialized services and attempted to design a newer system that included the standardization of relevant diagnoses through the use of a "clinical medical officer" and national diagnostic codes to classify children in the community. An information form completed by a parent accompanied this classification and was stored in a computer database. They reported on the early

successes of implementing their system, namely, the minimal increased workload for the clinical medical officer, the ease of computer program use, and the reduction of inaccuracies regarding patient information. However, the investigators noted a concern that is still present today, namely, the potential for some unauthorized individuals to have access to a database filled with sensitive medical data. Despite its successes, one of the primary challenges with such a system is the dependence on caregiver participation for the program to succeed.

Later work by Colver and Robinson,⁷ again in the UK, reviewed the use of these registries, in the UK and their inherent limitations. Colver and Robinson noted the problems with such registries, but more importantly provided some initial starting points for the development of an effective and useful registry for the CSHCN population. They identify the important objectives for such a registry, which seem to hold true to today and need to be considered in the development of future registries. They state that registries are to: "(a) improve the care of individual children; (b) improve the planning of services for children; and (c) improve opportunities for research and epidemiology."⁷

More recently, in 2001, Montgomery and Miller⁸ looked at the use of one state's birth defect registry and the identification of children with various diagnoses, both medical and environmental, which likely put them at risk for developmental delay. The Colorado Department of Public Health and Environment developed a public health program entitled Colorado Responds to Children with Special Needs (CRCSN) in 1989. The CRCSN is a centralized, statewide registry of children with birth defects, developmental disabilities, or risks of developmental delay. One year later, the Community Notification and Referral Program (CNRP) in Colorado was developed by a task force to link children and their families identified through the CRCSN with local agencies to give them information on local resources. To examine the impact of the CNRP, CRCSN reviewed data from 1621 children in their registry who were referred to local agencies in 1998. They found that 34.1% of the families were contacted via local agencies and 46.9% of those contacted were referred to early intervention or other services via the CNRP. However, in a telephone survey conducted by CRCSN, 65.4% of families with children identified as being at risk said they had learned about services they had not been aware of through the CNRP. The authors concluded that the existence of both the birth defects registry as well as a notification program can help to prevent children from "slipping through the cracks" and may be a model for other states.⁸

as storage vials and identification stickers for the home, but also arranges for online accessible data. In addition, local EMS is provided with a notification letter, alerting them to the presence of a CSIICN in their community and providing access to their EIF before a medical emergency occurs.¹⁴

With an ever-increasing number of CSHCN in our communities, there has been an added focus on how best to train prehospital providers regarding their care. Despite the existence of various focused training programs, such as Special Children's Outreach and Prehospital Education developed by the EMS and Children with Special Health Care Needs Project at Children's National Medical Center in Washington, DC, there is still a dearth of such programs throughout the country. A list of resources currently available to the prehospital provider is shown in Table 1. To date, few studies have examined the impact of these programs on prehospital provider knowledge and/or change in practice in caring for medically complex patients. One study noted that even in instances of caring for CSHCN patients, simple basic life support (BLS) procedures were much more common than advanced procedures.¹⁵ Such research suggests that despite their medical complexity, BLS services may be all that is needed during prehospital encounters with the CSIICN population. More research specifically identifying targeted training points for prehospital providers could be of benefit in the assessment and creation of further training tools for EMS providers.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THE IMPORTANCE OF A MEDICAL HOME

Although the prehospital provider will be called upon to care for a number of CSIICN, quality care begins with the creation of a medical home for these children. The AAP defines a medical home as a place that "provides care that is accessible, comprehensive, coordinated, compassionate, family-centered, community-based, and culturally effective."¹⁶ Recently, the AAP and American Academy of Family Physicians identified the existence of a medical home for all children as a key strategic goal.¹⁷ For children with chronic medical conditions, coordinated care is recognized as increasingly important, providing better outcomes and fewer hospitalizations for these children through a proactive and planned approach.¹⁶

Benedict¹⁸ used data from the 2000-2001 National Survey of CSHCN to identify characteristics of high quality medical homes and their resultant

effect on CSHCN access to therapeutic and supportive services. The results of their study showed that high-quality care delivered by medical homes was associated with a significant decrease in unmet needs. However, having a poor-quality medical home presented a significant barrier to accessing both therapeutic and supportive services.¹⁸ Providing such services for these children results in improved health, and one would assume a resultant decrease in the reliance on local EMS. In addition, these primary medical homes and joint subspecialty clinics often treat a large number of these children and could be used by local EMS agencies and prehospital providers as a terrific source of information and training. Creating partnerships between medical homes in the community and EMS can better prepare prehospital providers to care for these children as problems arise.

TRANSPORT OF CSHCN

Given the factors just discussed, emergency transport of CSHCN to medical care requires that the prehospital provider has adequate information in caring for the patient to provide the best level of care during transport to the receiving facility. Lerner et al¹⁹ recently examined aspects of prehospital care for CSIICN, acknowledging the need for regionalization of care that may also result in the creation of specific transport teams for these medically complex children. Although the local prehospital provider would still occasionally respond to the home of a CSHCN in the event of a medical emergency, the goal would be for the existence of regional transport teams that can then transport these patients from community hospitals to specialized facilities where they receive their routine subspecialty care. These transport teams in partnership with specialized care facilities would participate in the "medical home" of these children by providing consistent, reliable, timely, and family-centered care.¹⁹

It may be that these specialized pediatric transport teams improve overall care and outcomes. In one study, Orr et al²⁰ reviewed more than 1000 pediatric transports and found that unplanned events, including airway-related problems, cardiopulmonary arrest, hypotension, and loss of intravenous access were substantially more common among patients transported via nonspecialized teams when compared with specialized teams (61% vs 1.5%). More importantly, mortality was higher among patients transported by a nonspecialized team compared with a specialized transport team (23% vs 9%).²⁰ Other factors such as cost or

The ongoing challenge has been how best to identify children at risk for needing special services. However, identifying these children goes beyond assessing their families' ability to access resources as one can imagine a variety of settings in which identifying CSHCN would be essential, from reaching the most at risk in a pandemic to aiding in evacuations. A comprehensive registry of CSHCN could be used by prehospital providers to perform a variety of tasks. Farel et al⁹ attempted to see if local state birth defect registries could be used to identify certain groups of CSHCN. Although this system would be limited to those children with special needs that were born with birth defects, their assumption was that many states likely had surveillance programs in place that could easily be used for identification and referral to specialized programs. They surveyed all 50 states including Washington, DC, and Puerto Rico, and received completed surveys from all groups. Upon review of their data, only 32 of 52 states had birth defect surveillance programs, and only 13 of those 32 had identification and referral plans in place. Although current plans in place seemed to indicate an overall lack of identification and referral through birth defect registries, it is important to note that the 16 states planning a surveillance program for birth defects were all planning incorporation of identification and referral systems as part of their planned surveillance program. Interestingly, echoing the sentiments of O'Mahoney, they noted that respondents stated that confidentiality issues were one of the major barriers to implementing such a system.⁹

Although certain special registries of CSHCNs have had some successes, much more work is needed in this field. Technology has advanced our ability to identify these children in their communities; however, there still seems to be great concern among parents of CSHCN regarding their confidentiality and privacy. Some groups are currently looking toward using state immunization databases to identify at-risk children.¹⁰ In addition, in Utah, there is work on the statewide level to create electronic versions of an EIF with an accompanying statewide database. The use of EIFs as well as this unique program in Utah will be discussed in more detail in the following section.

THE ROLE OF CAREGIVERS, EIFS, AND TRAINING PROGRAMS AS RESOURCES TO PREHOSPITAL PROVIDERS

In the prehospital setting, family members and caregivers can serve as an excellent source of knowledge regarding the child's routine care. It is

important for the prehospital provider to recognize that caregivers manage most issues that arise in these children in the home. In addition, they are often well versed in the maintenance and operation of their medical devices and technology. As such, the prehospital provider should view them as a valuable resource during their time caring for these children. Although these caregivers should serve as the first line for their medical history, routine care, and maintenance of their medical devices, at least 1 study has shown that many caregivers may have limited understanding of the child's medical conditions. Carraccio et al¹¹ showed that more than half of caretakers of CSHCN at a specialty clinic visit were unable to report some of the child's specific diagnoses and almost 30% could not provide a list of medications. Interestingly, in this same study of 49 caregivers, none of the children wore any medical identification jewelry.¹¹ Even as primary caregivers are a primary source of information regarding the child's care and accompanying medical technology, EMS agencies should also engage their local hospitals to facilitate the exchange of health information for these complex patients in their community. Further study on how best to approach this problem is still needed.

Given the concerns that family members and caregivers may not be as knowledgeable regarding the child's care as one would expect, especially during times of duress, both the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians recommend these families use an EIF for CSHCN. In addition, many individual state EMS for Children agencies recommend parents to place a copy of the EIF in the freezer of the child's home, so that it can be located quickly and easily in the event of a medical emergency. Even in the presence of a caregiver, it is recommended that the prehospital provider ask for this document as it can prove invaluable regarding the child's care in transport and can aid the prehospital provider in their assessment and reporting to the child's eventual destination; the information may also provide useful to hospital-based emergency care providers. This is especially the case when the parent is not the primary caregiver and/or the person with the child may be distracted in the midst of an emergent situation.^{12,13}

As previously mentioned, Utah's EMS for Children program has developed an initiative aimed at generating more widespread use of the EIF system, integrating these forms with an online database, and providing access to the data. This program, known as the Children's Health Information Red Pack Program, or CHIIRP, not only provides EIFs as well

the acuity of the emergency must be considered when dispatching high-level teams for routine transport. Lerner et al¹⁹ recommend the routine use of these teams for all but the most acute of emergencies. In these cases, community EMS agencies should be called upon to take these children to health care facilities given their proximity to the patient's home. Studies are needed to examine the potential benefit of this type of planned approach to EMS dispatch and coordination of transport.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN DISASTERS

Although the AAP has continually stressed the importance of the EIF as well as the medical home, these tools require ongoing updating if they are to aid in the event of a disaster. Ideally, the AAP recommends that EIFs be updated frequently and should include some degree of a personal or family disaster plan. Such plans include but are not limited to the location and access to generator power for children dependent on electricity to maintain their medical equipment along with surplus supplies and evacuation plans. These plans should be created

with the assistance of the primary care provider located within the medical home.²¹ Although the planning stages before a disaster seem to require little involvement on the part of the prehospital provider, the reality is that those prehospital providers may likely be called upon to transport, evacuate, and care for these children. Prehospital providers and statewide emergency response agencies will likely be on the front lines in a given disaster as well as highly involved in the coordination and planning of shelters where these children are likely to present in the setting of a disaster in a given community. 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. The hope is that these children will present in optimal health in these situations; however, it is much more likely that they will require significant medical resources to relocate them in the event of a disaster that leaves their residence uninhabitable. As such, CSHCN need to be an integral consideration within the community's preparedness plan from the beginning. The prehospital provider and the state agencies with disaster preparedness responsibilities should take

TABLE 1. Educational programs available to the prehospital provider.

Program	Online Resource
Special Children's Outreach and Prehospital Education	http://www.childrensnational.org/files/PDF/EMSC/PubRes/Scope_Instructor.pdf
A full-day course for prehospital providers that covers the care and management of CSHCN. Developed by the EMS and Children with Special Health Care Needs Project at Children's National Medical Center in Washington, DC. Instructor's manual is available via the link.	
Teaching Resource for Instructors in Prehospital Pediatrics	http://webdoc.nyumc.org/nyumc/files/cpem/u3/trippbls.pdf
Developed at New York University, Langone Medical Center, with input from subject matter experts from across the country and incorporating American Heart Association guidelines.	
Utah Telehealth	http://www.utahtelehealth.net/education/ems_childrens/
Developed by pediatric emergency medicine physicians at the University of Utah. Consists of 8 online learning videos covering topics from general pediatric prehospital care, to CSHCN.	
Pediatric Education for Prehospital Professionals	http://www.peppsite.com/

Sponsored by the AAP, this course comes in 9.25-hour BLS and 16.75-hour advanced life support versions for a wide array of prehospital providers and covers a range of general pediatric topics.

into consideration all possible scenarios. This may range from simple planning, such as the availability of 12 volt inverters to use car batteries as a back-up power source if needed, to more complex issues such as a central electronic EIF repository. In addition, there must be some degree of training provided so that when the eventual disaster does strike in a given community, frontline responders will be well prepared and have the necessary resources, in the form of both supplies and knowledge, to succeed.¹³

Families of CSHCN use a wide array of electricity-dependent resources during the day-to-day care of their children, some providing comfort and optimizing care and many providing life-sustaining therapies. Sakashita and Matthews²¹ attempted to identify how frequently these families required electricity for their "technoelectric dependent children." The results of their 50-patient survey showed that these patients used more than 150 electrical devices. The families and caregivers identified a home ventilator, oxygen concentrator, and feeding pump as the 3 most important devices in the house requiring electricity in 35 of the 50 children surveyed. However, only 19 caregivers knew if a battery backup for these devices existed, and only 22 of the 50 families had a plan in place should an electrical power failure occur for a prolonged period.²¹

One study examined regional variation in degree of preparedness between families caring for CSHCN and the impact of an educational intervention. There was no significant difference with regard to overall disaster preparedness when comparing families from Alabama and Florida. However, the investigators did find a significant improvement in disaster planning after a very brief (10-20 minutes) intervention presented by a trained health educator that included information on 3 key elements of disaster preparedness: "(1) being informed about potential disasters, (2) completing an emergency preparedness plan with family members, and (3) compiling a home disaster kit."²² In addition, families received handouts from the Federal Emergency Management Agency, the American Red Cross, and the Department of Homeland Security on disaster preparedness as well as a Family Emergency Plan form from the Department of Homeland Security and the Emergency Information Form for Children with Special Needs from the AAP. Although the study did show an increase in knowledge at follow-up 30 days later, further study over a longer timeline would be of benefit to see how such an educational intervention continues to impact the readiness of these

families. The prehospital provider, especially those that frequent certain households with CSHCN, could be an excellent resource to provide such information to these families. However, this has never been specifically investigated.

Ultimately, the caregivers of CSHCN have been shown to be poorly prepared for eventual disasters, in particular for prolonged periods of power outage. However, very simple and brief interventions can lead to a significant improvement in their level of preparedness. These families will likely rely heavily on EMS and the prehospital provider in a number of different ways during the course of a disaster.

UNANSWERED QUESTIONS

Although further research is needed to specifically address the needs and challenges in this population, it seems that work should be focused on 3 areas relevant to the prehospital provider. First, the creation and dissemination of an electronic EIF that provides up-to-date information generated by both providers in the medical home and parents and is also compliant with patient confidentiality issues yet also widely accessible to prehospital providers. Programs such as Utah's CIIIRP are making strides in the right direction, but difficulty with enrollment and involvement from families with CSHCN continues to be a problem, largely for the reasons outlined from earlier efforts in the UK. Although some groups have investigated the use of immunization registries, a largely pervasive and accessible database of a sizable group of pediatric patients, no current studies appear to be looking at the feasibility of making these immunization registries serve this dual purpose. Second, improved preparedness for families with CSHCN through educational efforts and community planning would likely improve care in both large scale and individually focused disasters. Finally, the continued increase in regionalization and specialization of pediatric transport teams would likely remove some of the burden from prehospital providers regarding the care of these patients.

SUMMARY

Although the prehospital provider may not be asked to care for CSHCN on a daily basis, by familiarizing themselves with certain aspects of their care, they can more effectively provide life-sustaining interventions. Many have made similar recommendations to those listed above. Many studies have shown the benefits of pediatric specific

transport teams when transporting CSHCN. A thorough review of regional resources should be undertaken by prehospital providers when caring for these children to ensure that regional resources for specialized transport are being used appropriately. However, it must be again reinforced that using available resources, in the form of caregivers familiar with the child, EIFs, and specialized care facilities in the area, gives prehospital providers the necessary tools to maintain a patient during transport or until a specialized transport team arrives.¹⁹ It is our hope that the topics discussed here will continue to grow in their scope and accessibility, so that one day an easy-to-access repository of EIFs will be available to prehospital providers along with plans in place to arrange for specialized transport teams and regional care, thus further improving the care of this ever-growing population. ☒

REFERENCES

1. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Available at: www.childhealthdata.org. Accessed March 27, 2013.
2. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* 2011;127:529–38.
3. Berry J, Hall M, Hall D, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *Arch Pediatr Adolesc Med* 2013;167:170–7.
4. Feudtner C, Villareale NL, Morray B, et al. Technology-dependency among patients discharged from a children's hospital: a retrospective cohort study. *BMC Pediatr* 2005;5:8.
5. Emergency Medical Services for Children National Task Force on Children with Special Health Care Needs. EMS for children recommendations for coordinating care for children with special health care needs. *Ann Emerg Med* 1997;30:274–80.
6. O'Mahony MC, Allsop M, Heath C, et al. The register of children with special needs: an approach. *Publ Health* 1987; 101:9–15.
7. Colver A, Robinson A. Establishing a register of children with special needs. *Arch Dis Child* 1989;64:1200–3.
8. Montgomery A, Miller L. Using the Colorado Birth Defects Monitoring Program to connect families with services for children with special needs. *Teratology* 2001;64:S42–6.
9. Farel A, Meyer R, Hicken M, et al. Registry to referral: using birth defects registries to refer infants and toddlers for early intervention services. *Birth Defect Res* 2003;67:647–50.
10. American Academy of Pediatrics. Pediatric preparedness resource kit inspired by the H1N1 pandemic: strengthening pediatric and public health partnerships. Available at: <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Documents/PedPreparednessKit.pdf>. Accessed January 15, 2014.
11. Carraccio C, Dettmer K, Lynne du Ponte M, et al. Family member knowledge of children's medical problems: the need for universal application of an emergency data set. *Pediatrics* 1998;102:367–70.
12. American College of Emergency Physicians. Emergency information form for children with special health care needs. *Ann Emerg Med* 2010;56:315–6.
13. American Academy of Pediatrics Committee on Pediatric Emergency Medicine and Council on Clinical Information Technology; American College of Emergency Physicians Pediatric Emergency Medicine Committee. Emergency information forms and emergency preparedness for children with special health care needs. *Pediatrics* 2010;125:829–37.
14. Dalrymple T. The CHIRP program. EMSC connects. Utah State EMSC Newsletter. 2013; Vol. 2, Issue 9:2–4. Available at: <http://health.utah.gov/ems/emsc/newsletters/2013-09.pdf>. Accessed January 15, 2014.
15. Spaite DW, Conroy C, Karriker KJ, et al. Improving emergency medical services for children with special health care needs: does training make a difference? *Am J Emerg Med* 2001;19:474–8.
16. American Academy of Pediatrics Medical Home Initiatives for Children with Special Needs Project Advisory Committee. The medical home. *Pediatrics* 2002;110:184–6.
17. Future of Family Medicine Project Leadership Committee. The future of family medicine: a collaborative project of the family medicine community. *Ann Fam Med* 2004;2:S3–S32.
18. Benedict R. Quality medical homes: meeting children's needs for therapeutic and supportive services. *Pediatrics* 2008;121:e127–34.
19. Lerner CF, Kelly RB, Hamilton LG. Medical transport of children with complex chronic conditions. *Emerg Med Int* 2012;2012:837020. <http://dx.doi.org/10.1155/2012/837020>.
20. Orr R, Felmet KA, Han Y, et al. Pediatric specialized transport teams are associated with improved outcomes. *Pediatrics* 2009;124:40–8.
21. Sakashita K, Matthews W. Disaster preparedness for technology and electricity-dependent children and youth with special health care needs. *Clin Pediatr* 2013;52:549.
22. Baker L, Cormier L. Disaster preparedness and families of children with special needs: a geographic comparison. *J Commun Health* 2013;38:106–12.