Recommendations for Emergency Care Plans
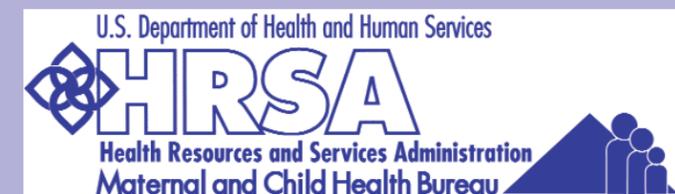
for Children with Special Health Care Needs

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau

Recommendations for Emergency Care Plans

for children with special health care needs

Introduction

In the United States, over thirty percent of the children under the age of 18 years, or approximately 20 million children, have one or more chronic health conditions.[1] Eighteen percent of U.S. children in this age range, or 12.6 million children, "have a chronic physical, developmental, behavioral or emotional condition and require health and related services of a type or amount beyond that required by children generally."[2] Children with special health care needs (CSHCN) are at much greater risk for increased health care utilization[3, 4] and in particular for emergency care.[5] For these children and their families, emergency situations pose a particular challenge in access to health care providers with knowledge of their particular condition and collaboration among all providers and the child and family to manage the emergent situation effectively.[6] According to Ireys, seven critical areas concern all families with special needs children: access to care, appropriateness of services, comprehensiveness of services, care coordination, continuity of care, relation to community, and the degree to which services and the service system are family-centered.[7] While the importance of providing coordinated, comprehensive care to children has been well-documented, it often remains difficult to accomplish. The process is often slowed or impeded by a host of barriers–institutional, relationship, cultural, political and geographical.

To better prepare children with special health care needs and their families and other providers of care, the Emergency Medical Services for Children (EMSC) program encourages families and other caregivers of CSHCN to develop a written, accessible and up-to-date emergency care plan. This emergency care plan would guide the care of the child with special health care needs prior to and during emergency situations.[8] To promote the development of these emergency care plans, EMSC contracted with the National Association of Children's Hospitals and Related Institutions (NACHRI) to develop guidelines and recommendations on emergency care plans for CSHCN.

The process of developing the guidelines and recommendations had several phases: (1) a review of current literature on emergency care for children with special health care needs spanning the last ten years; (2) collection and analysis of practice guidelines and emergency care plans for children with special health care needs from NACHRI member hospitals/health systems (with a particular focus on children with asthma and children with heart conditions); and (3) a consensus meeting of experts involved in the health care of children with special needs to review the preliminary work, develop the guidelines and make recommendations.

Review of Literature

The literature review focused on publications that related to programs that address the emergency care needs of children with special health care needs. In particular, information on the development of emergency care guidelines or emergency care plans for use by families, primary care providers, schools, community organizations and other caregivers was collected. Materials on discharge planning for CSHCN and family-centered care also were reviewed. The review focused on models related to children with asthma and children with heart conditions.

The literature revealed little published information or research on the use of emergency care plans for children with special health care needs. A further review of state activities in this area suggests a "body of fugitive literature" on emergency care plans. Several states, including Alaska, Massachusetts, New Hampshire, New Mexico, New York, Ohio, Oregon, Rhode Island, Utah and Wisconsin, and the District of Columbia, have developed tools and guidelines for the emergency care of children with special health care needs. Much of this work has been supported through funding by the EMSC program. The work includes: (1) discharge planning manuals, (2) multiple formats for information needed to care for a child with special health care needs in an emergency, (3) systems for linkages to community based first responders, (4) profession specific training programs and (5) emergency readiness in primary care offices, schools and day care centers.[9]

The literature on discharge planning for CSHCN was more comprehensive and focused on the content, development and utility of discharge planning tools, education, and family and interdisciplinary provider participation in the process of discharge planning. The need for discharge planning that is based on the expressed needs of the child and family, especially in the areas of physical aspects of care, psycho-social needs and financial issues was discussed in the literature.[10,11] The format of information and amount of information to be presented to the child/family so as to optimize use of information also was discussed.

Family-centered care was explored as a framework for the development, use and evaluation of emergency care plans for CSHCN. Family-centered care is a philosophy of care that places children and families, rather than the professional or agency, as the focus of the health care system. This philosophy of care serves as a guide for the processes of development, implementation and evaluation of emergency care plans for CSHCN, e.g. recognition of the family as the constant in the child's life, facilitating parent-professional collaboration, and sharing of information with families.[12]
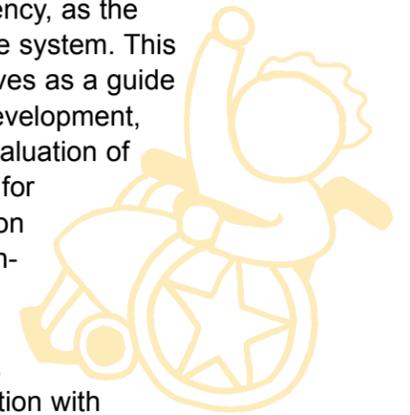
Information was requested from all NACHRI member hospitals/health systems concerning the tools they use to guide care, discharge planning and education for CSHCN and their families. In addition, hospitals were asked about their use of emergency care plans for 1) CSHCN in general, 2) children with asthma and 3) children with heart conditions. Specific information requested included: (1) identification of individuals responsible for coordination of care and discharge planning for these children, (2) the individuals involved in the development of tools, (3) the content of tools, (4) the formats used to convey information to children and families, (5) the distribution of information developed and (6) the systems for monitoring and evaluation of the tools and education materials developed. Information was obtained concerning:

CSHCN in general	12 hospitals
Children with heart conditions	23 hospitals
Children with asthma	63 hospitals

The analysis of information from NACHRI member hospitals/health systems demonstrated that much is currently being done to address the health care needs of CSHCN and their families. Protocols, practice guidelines and care paths in many cases were developed and provide the basis of care for many CSHCN. The development of the tools to guide care was more prevalent for children with asthma, whose care impacts a significant use of resources for children's hospitals/health systems. Another factor in the development of institutional guidelines appears to be the development of national pediatric guidelines for care upon which institutional tools can be built and that provide a basis for comparison in outcomes. Most of the emphasis for the

development of tools to guide health care practices has been on the more costly inpatient and emergency room segments of care. However, the care provided outside the traditional inpatient settings also is being included by many hospitals. Partnerships between children's hospitals/health systems, community-based providers of care and families continue to be developed and expanded in their scope.

Consensus Group Recommendations

The analysis of the current development and use of emergency care plans for CSHCN indicated that the practice is not yet developed to its full potential. While much relevant information is provided to families and other caregivers and providers of care, several key opportunities exist for providers across the EMSC continuum to work together with families to affect the care provided to all CSHCN.

The consensus group identified several key opportunities to consider to foster the successful development and implementation of emergency care plans for CSHCN, including:

1) expand involvement of families and a broader scope of providers from across the EMS continuum in the process

2) identify effective content and formats of emergency care plan information and systems for maintaining and updating information on a regular basis

3) develop systems to monitor and evaluate the use and effectiveness of emergency care plans.

1) Involvement of Families and Providers Across the Care Continuum

The emergency care plan should serve as a template for action by the child, family, and other caregivers/providers of care who may be involved prior to or during an emergency situation with a child with special health care needs. Individuals who play a role in the emergency care of the child should be involved in the process of development, implementation and evaluation of emergency care plans for CSHCN. This involvement is key to the successful use of these tools.

The philosophy of family-centered care (FCC) recognizes the family as the constant in the child's life. FCC encourages parent-professional collaboration for the care of the individual child as well as the development of programs of care and policies governing systems of care. The sharing of information with families in a complete and unbiased manner facilitates the partnership with the family as a full member of the team to plan and deliver care to the child with special needs. A primary goal of the family-centered approach to care is the empowerment of children and families with knowledge, training and resources to take charge of their own lives and manage care effectively.

Families are integral partners in the emergency care planning process. The first step in ensuring their participation is to recognize that they are members of the multidisciplinary team and play a central role in the decisions that are made. As family needs change, their time commitment to this process may not be consistent. This should not be viewed as a lack of interest, but should be understood. For families new to the process, pairing them with an experienced staff person, another parent, or family advocate to support them through the process and encourage their active participation may be helpful. Practical suggestions to facilitate family involvement in the process include the scheduling of team meetings at times that are convenient to the family, financial support for parking expenses for meetings and providing meals or child care for siblings during meeting times as necessary. Alternate methods for family involvement when they are unable to attend meetings should also be developed, such as phone contacts, personal contacts by a support person, and e-mail or written summaries of meetings. These attempts further reinforce their important role in the team process. Hospital based family advisory groups or community based family

advocacy groups can be used to heighten awareness of the need for emergency care planning for children with special health care needs.

Another key factor in the care of CSHCN is the coordination of multiple services required by the child and family within the system of care, rather than fragmented resources that may or may not work together to further the health goals of the child and family. Involvement of children, families and health care providers from across the continuum in all phases of emergency care planning can assist in this coordination of care. Based on the information from NACHRI member hospitals/health systems, some progress has been made as more families, primary care physicians, subspecialty physicians, hospitals staff from a variety of disciplines, and emergency room personnel are included in the process. The work in this area needs to be expanded. Opportunities exist to include key community-based providers of care, especially pre-hospital personnel and school-based personnel in developing tools to guide the care of CSHCN, such as emergency care plans. The National Association of School Nurses advocates for the development of an emergency care plan for each student with special health care needs in a school setting. The school nurse can play an active role in developing this plan of care.[13]

Community-based providers should be invited to participate in the emergency care planning process. This invitation should include a clear description of benefits of the process, goals, roles and expectations regarding the amount of time and other resources that may be involved. Alternatives to actual meeting attendance, e.g., conference calls, e-mail discussions or scheduled opportunities for input and review of emergency care planning materials may support the involvement of busy providers. Continuing education offerings for community-based providers need to focus on the need for emergency care planning for children with special health care needs. This strategy will help promote involvement by the community-based partners.

The initial development of the emergency care plan for each child with special health care needs often is challenging. Children with complex care needs face multiple transitions, both developmentally as well as across the continuum of care. Therefore, of equal concern is the maintenance of current information about the child and family to most effectively guide the interventions received by the child at times of emergencies. Given the multitude of changes occurring in the health care system, the idea that discharge planning at the times of hospital admissions is the sole time for information updates and family education is no longer valid. "Discharge planning cannot remain the process we once knew, a process that had a beginning and an end. Rather, as transitioners, we remain partners with the child and family across time and whenever circumstances indicate."[14] The use of technology to assist with these updates offers one solution to the issues. But with or without the use of technology, systems for developing and periodically updating information and providing supportive education for families could be built into the routine care received by the

child and family. Key opportunities for practice improvement identified include:

- identify responsibility among the family and members of the interdisciplinary health care team to complete initial emergency care plan information and provide periodic updates to information

- identify routine times for review and update of information as necessary, e.g., yearly well child exam set at the same time each year, first office/clinic visit post hospital discharge or emergency room visit, prior to each hospital discharge, or in sessions for development/evaluation of the child's Individualized Healthcare Plan (IHP)

- coordinate distribution of information related to the emergency care needs of the child with other systems of care, e.g. schools

There are numerous challenges to the development of emergency care plans. These include: (1) reimbursement for provider time, (2) resources necessary to develop and maintain emergency care plans, (3) family education, (4) confidentiality of patient specific information, (5) design of information systems to support dissemination and maintenance of emergency care plan information that are compatible with existing data systems, and (6) effective collaboration with those families who may be reluctant to have their child be labeled as having "special needs" or share child specific information via the emergency care plan.

After the emergency care plan is developed, timely distribution of this vital information to potential providers of care is important. The successful dissemination of emergency care plans for CSHCN must expand on two levels of care – care for the individual child and the

development of systems to provide access to information for a larger number of CSHCN.

At the level of the individual child, a plan for dissemination of the care plan to key players on the EMSC continuum should be developed by the family in collaboration with other members of the health care team. Opportunity to include more community based providers of care, such as primary care providers or subspecialty providers serving as the child's medical home, school nurses and emergency responders in the dissemination process exists.

As emergencies for a CSHCN can, and do, happen at any time and any place, further consideration of a process to access emergency care plan information should be considered in the analysis of care of the individual child as well as from a broader systems perspective for all CSHCN. Several key factors tie to the accessibility of information on the emergency care plan, including access to information on a 24 hour, 7 day a week basis, communication regarding the location of information, and portability of information. The identification of a common place for storage of information has long been advocated. It has been suggested to keep a copy of the emergency care plan in the freezer. This would be an easily found location and information would more likely be protected in case of natural disaster. Wallet sized cards can be easily carried by family members and providers of care. Magnetized stickers for posting on the outside of the refrigerator or other metal object can be used.

Technology provides other options to access and update care plan information for the child with special health care needs. Use of hand carried computerized systems can make information readily accessible for health care providers. The use of technology to centrally

store information about children with special health care needs is one strategy being used by a number of states. This information is collected and stored in centralized databases that are accessible 24/7 by health care providers responding to an emergency situation via computer, telephone, central dispatch system for EMTs or via fax to the health care provider in a school, office/clinic or emergency department location. Some health care provider systems have developed web accessible information regarding the CSHCN that is directly available to providers in multiple venues of care. Families should be involved in the development of these systems to assure permission for access to information and other issues associated with the confidentiality of information related to the individual child.

The literature review conducted for this project revealed surprisingly little published information on successful models for the development, implementation and evaluation of emergency care plans for CSHCN. Those involved in these processes need to be encouraged to share their experiences with colleagues through publication in professional journals and presentation at educational meetings at the local, state, regional and national levels to move the overall development, use and evaluation of these valuable tools and systems forward.

2) Effective Content and Formats for Emergency Care Plan Information

Families of CSHCN often become inundated with information about their child's condition and treatment. The information comes in a variety of formats and at various levels of legibility and understanding. SIMPLICITY is the key in providing information to assist families

to prepare for and act at the time of an emergency with their child. This concept of simplicity applies to several areas of the emergency care plan, including:

- ⟳ content of the emergency care plan

- ⟳ formats for critical content included in the plan

- ⟳ systems for maintenance of current information and access to plan information

Content of the Emergency Care Plan

Information in the emergency care plan for a child with special needs should:

- ⟳ target prevention and preparation for an emergent situation

- ⟳ identify initial symptoms for concern and response to escalating situations, and

- ⟳ provide first responders and emergency department personnel with critical information

Prevention of and Preparation for an Emergency Situation

The escalation of symptoms and emergency situations may be frequent in the life of some children with special health care needs. Prevention of emergency situations is a realistic and attainable goal. Family members and other caregivers must have the relevant information they need to effectively manage the health status of the child and prevent emergencies. This information includes:

A basic overview of routine treatments and medications needed to keep the child healthy: Information could be presented in the format of a daily/weekly routine for the

care of the child to be followed at home, school, etc.

A brief review of situations to avoid in order to prevent emergency situations for the child: Allergies (e.g,. to foods, medications), environmental concerns (home or outside environment) and/or activities that may trigger or exacerbate symptoms in the child should be identified.

Basic safety tips relevant to the developmental age and physical and/or cognitive challenges faced by the child.

There are also steps that the child, family and other caregivers can take to prepare for an emergent situation that may assist in the smooth delivery of health care and other services at that time. The emergency care plan should provide basic information to assist families in building relationships and exchanging information with individuals involved in responding to an emergency situation with the child with special health care needs.

Develop a checklist and contact information for services needed in an emergency situation. Utility companies, medical equipment suppliers and local fire/rescue personnel may respond to a call for assistance in an emergency situation. Families should contact these services and share plans for emergency care services for their child.

Educate caregivers and providers who may respond in an emergency situation, e.g. school personnel, fire/rescue personnel or local emergency department personnel and share care plan information with them. The care plan should list these individuals with contact information. For local fire/rescue personnel this education may include a home visit to acquaint them

with the home environment and the child to facilitate their response in an emergency situation.

Plan to handle logistics associated with an emergency, e.g. local emergency departments and transportation options included in the family's health care plan provider network, family travel to/from the hospital, care for other children in the family, and notification of other family members. A checklist could be provided in this section of the care plan to help families think of issues they need to consider and plan for in the event of emergency.

Identification and Initial Response to Escalating Symptoms

The information needed in an emergency can be summed by three simple questions: "What do I look for?", "What do I do?", and "Who do I call?". While the questions may be simple, presenting the answers in a format that aids in the response to an emergency can be challenging. The watchword to give information to those who may need to use it in an emergency is SIMPLIFY:

SIMPLIFY by giving only key information

SIMPLIFY by presenting information that is easily understood and followed in an emergency. The use of simple decision trees or other graphic displays of possible symptoms with the responses to be followed by the child or caregiver may be helpful

SIMPLIFY by giving clear and concise direction on when to seek additional help and how to contact additional help

Additional information to consider for the emergency care plan includes:

Assessment of the child

- Baseline vital signs and observations regarding the child, including functional abilities, communication and behavioral/mental status

- Signs and symptoms to look for that may signal an emergent situation in the child's condition

Initial Response to Emergency

- Action plan – what steps to take when signs and symptoms of an emergency develop

- Guidelines for changing intervention based on the ongoing assessment of the child's condition

Calling for Help

- Conditions that warrant assistance by emergency medical personnel.

- Who to contact and how to contact them

Information for First Responders and Emergency Department Personnel

A key segment of the emergency care plan is information to guide first responders and emergency department providers in their initial treatment of the child with special health care needs. This is especially important for children who travel long distances for subspecialty care as local emergency providers may not be as familiar with the child and his/her particular health care concerns and individualized treatment plan. Also, in today's mobile society, the child and family may find themselves facing an emergency situation when away from home on business, vacation or school trips. Having basic information to give first responders and emergency department personnel in these situations could be critical to the effective and timely treatment of the child. The American Academy of Pediatrics (AAP) and American College of Emergency Physicians (ACEP) developed an Emergency Information Form (EIF). This form is a simple, standardized 2-page summary of information considered to be most relevant and helpful for these providers in an acute emergency with a child with special needs.[15, 16] The EIF includes basic demographic and contact information, diagnoses, past procedures and baseline physical findings for the individual child, management data and common presenting problems with suggested management in an emergent situation. The EIF is a critical component of the overall emergency care plan developed for the child with special health care needs.

Formats for Information on the Emergency Care Plan

Families of children with special health care needs are often inundated with information about their child's health condition, treatment, providers of care, etc. However, in an emergency, it is imperative that they and other caregivers and providers of care have a concise plan for action presented in an understandable way. The information to guide their actions in an emergency must stand out from all other information in a clear, recognizable way, such as the use of bright colored paper or packaging that sets the emergency information apart from all other information. Special attention needs to be paid to the literacy level of information. Information needs to be available in multiple languages that reflect the patient population of the area to foster use by all families. The use of large print and pictures can demonstrate action to be taken which will increase the understanding and utility of such information. Families suggest the use of decision tree or action plan formats that simply tell the story of the relationship between what they see happening with their children and the actions to be taken.

For health care providers, concise and essential information is paramount. It is important to focus on assessments, interventions, diagnostic testing and evaluation of the SPECIFIC child and family. The use of the check box format with minimal narrative that can be easily scanned is recommended. This format is extremely helpful to providers working with an unfamiliar child, especially in situations where time is paramount to the treatment of the child.

3) Development of Systems to Monitor and Evaluate the Use and Effectiveness of Emergency Care Plans

Although many NACHRI respondents had developed emergency care plans for certain CSHCN, only a few hospitals reported systems to monitor their use and effectiveness. There are numerous opportunities to develop and or update care plan information and evaluate the use and effectiveness of such plans. Opportunities include: office/clinic visits with the child's primary care provider and subspecialty providers, emergency room visits, and evaluations of EMS activities. Feedback to all individuals for whom the form's information was targeted helps to constantly improve the effectiveness of the emergency care plan.

Evaluation of care plan effectiveness could include the following parameters:

Family satisfaction

- Process for completion/updating of emergency care plan information
- Utility of information provided
- Ease of use of information provided

Provider satisfaction

- Process for completion/update of emergency care plan information
- Access to information
- Utility of information provided
- Ease of use of information provided

Utilization and cost of services for CSHCN

- Decrease in services due to use of information provided to families and providers, including:
  - Primary care office/clinic visits
  - Subspecialty office/clinic visits
  - ER visits
  - Hospital admissions and/or LOS
  - Measures of health status, morbidity

Conclusion

All children needing emergency care have unique needs. Medical emergencies pose a particular challenge for the over 12 million children with special health care needs in the United States and their families. An emergency care plan should be developed for every child with special health care needs that addresses three critical areas for action: (1) prevention and preparation for an emergency situation, (2) identification and initial response to escalating symptoms and (3) emergency information for first responders and emergency department providers.

Several key opportunities exist to promote the effective development, use and evaluation of emergency care plans for children with special needs: (1) increase involvement of families and providers from across the continuum of care in emergency care planning, (2) provide effective content and formats for emergency care plan information and (3) develop systems to evaluate the use and effectiveness of emergency care plans.

Numerous challenges to the development and use of emergency care plans for children with special health care needs remain, but the goals are clear – children, families and health care providers that are better prepared to prevent and respond to a medical emergency for a child with special health care needs, and better outcomes of care for this vulnerable population of children.

Prevention and Preparation for an Emergency Situation

Prevention

- Overview of routine treatments and medication needed by the child
- Review of situations/triggers that might lead to emergency situations
  - Allergies
  - Environmental issues
  - Activities
- Basic safety tips – relevant to developmental age and physical and/or cognitive challenges faced by the child

Relationship Building

Communication and Education

- Notification and education of services that may be needed in an emergency
  - Utilities
  - Medical equipment supplies
  - Local fire/rescue
- Plan for information sharing with community based providers and schools/daycare personnel

Emergency Logistics

- Transportation for family to/from emergency facility
- Childcare for other children in family
- Family notification
  - Process
  - Telephone numbers
- Listing of emergency facilities and transportation services covered under child's health plan

Identification and Initial Response to Escalating Symptoms

Content

Assessment of the Child

- Baseline vital signs and observations, including functional abilities, communication and mental/behavioral status
- Signs and symptoms of an emergency situation for this child

Initial Response to Emergency

- Action plan – steps to take at the development of signs/symptoms of an emergency
- Guidelines for changing intervention based on ongoing assessment of the child's condition

Calling for Help

- Guidelines for recognizing the need to call for assistance
- Who to contact for assistance with contact information

Format

For Families

- Package emergency information in an easily recognizable way that separates it from other information provided, e.g., use of brightly colored paper
- Use large print and pictures demonstrating actions to be taken
- Use decision tree or action plan formats
- Evaluate literacy level; provide information in multiple languages

For Emergency Providers

- Provide assessments and interventions that are specific for the child
- Use check boxes or other formats that allow for easy review of information

Emergency Information Form for Children With Special Needs

		Date form completed By Whom	Revised	Initials
American College of Emergency Physicians®	American Academy of Pediatrics		Revised	Initials

Name: Birth date: Nickname:

Home Address: Home/Work Phone:

Parent/Guardian: Emergency Contact Names & Relationship:

Signature/Consent*:

Primary Language: Phone Number(s):

Physicians:

Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:

1.   Baseline physical findings:

2.

3.   Baseline vital signs:

4.

Synopsis:
                                                   Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

Significant baseline ancillary findings (lab, x-ray, ECG):

1.
2.
3.
4.   Prostheses/Appliances/Advanced Technology Devices:
5.
6.

Management Data:

Allergies: Medications/Foods to be avoided   and why:

1.
2.
3.

Procedures to be avoided   and why:

1.
2.
3.

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: Print Name:

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