GETTING STARTED, STAYING INVOLVED:

EMSC Emergency Medical Services for Children NATIONAL RESOURCE CENTER

PRODUCED BY: THE EMSC NATIONAL RESOURCE CENTER

An EMSC Toolkit for Family Representatives

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The EMSC National Resource Center, located just outside Washington, DC, was established in 1991 to help improve the pediatric emergency care infrastructure throughout all 50 states, the District of Columbia, and the five U.S. territories. The NRC is housed within Children's National Medical Center, one of America's leading pediatric institutions serving sick and injured children and their families. In 2008, the NRC applied for its fourth (multi-year) funding award to provide support to the Federal EMSC Program.

The Federal EMSC Program is designed to ensure that all children and adolescents – no matter where they live, attend school, or travel – receive appropriate care in a health emergency. It is administered by the U.S. Department of Health and Human Services' Health Resources and Services Administration, Maternal and Child Health Bureau. Since its establishment, the Federal EMSC Program has provided grant funding to all 50 states, five U.S. territories, and the District of Columbia.

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EMSC Emergency Medical Services for Children NATIONAL RESOURCE CENTER

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In Loving Memory of Skylar Grayce Jarreau

As a parent or guardian, we always want what's best for our children. We strive to provide them with everything they need to be healthy and safe. Despite our best efforts, children may be affected by a tragic accident or illness. When that happens, we want them to have the best medical care. We may take it for granted, that once our child reaches the hospital, the emergency personnel will have all the equipment and expertise to help make them well.

As an educated mother of two children, I never fathomed that our local hospital would not be equipped to provide my child with the appropriate life sustaining treatment necessary for her to overcome injuries sustained in an accident. Our local regional hospital lacked the resources my child needed, necessitating her transfer to a larger facility. However, it was a lack of planning and preparation that ultimately cost my daughter her life.

In September of 2003 my 8-month-old child, Skylar Grayce, sustained an abdominal injury as a result of an adult tripping and falling on her. Shortly after the accident Skylar began demonstrating signs of shortness of breath. I immediately took her to our pediatrician. He examined her briefly and requested she be directly admitted to our local hospital for observation and x-rays. After an almost two hour wait for x-rays, we learned that Skylar sustained an internal abdominal injury requiring surgical repair. Our local hospital did not have pediatric surgeons on staff nor a pediatric intensive care unit (PICU), which physicians believed Skylar would need for aftercare. Therefore, it was decided that it would be in Skylar's best interest to transfer her to a hospital with resources that could better accommodate her unique pediatric needs.

Upon learning the extent of Skylar's injuries and being informed that she would have to be transferred, I was a little uneasy to say the least. However, after speaking to friends and loved ones, I was reminded we were less than an hour away from two of the best pediatric hospitals in the state. I was a little relieved and confident that Skylar would now receive the best possible care. I was not prepared for the time and effort it would take for a hospital to accept and take care of my baby.

The first hospital was contacted. After an hour the hospital responded that it was not in a position to accept Skylar because of a full PICU and two other babies were awaiting admission. A second hospital was contacted and they agreed to accept Skylar. I quickly learned that the accepting hospital would be sending their own transport team to pick her up because they were better equipped to care for Skylar in the event something went wrong during the transport. That sounded okay in theory but the roundtrip would take two hours. Two additional hours of critical time would pass.

Three hours after receiving word from the accepting hospital the transport team arrived. They began examining Skylar and preparing her for transport. Once Skylar arrived at the accepting hospital she was prepped and went into surgery approximately ten hours after the initial examination by medical personnel. It took surgeons two hours to repair her internal injuries. She fought a strong battle over the next few days and the hospital provided extensive resources to help her recovery, including extra corporeal membrane oxygenation, a heart-lung bypass procedure. In spite of these extreme efforts, her body could not fight any longer. Due to complications, Skylar's life support was terminated on a Sunday afternoon at 3:10 p.m.

Skylar's death did not result from the accident. It was the result of precious time lost in her treatment. She died of heart failure caused by the extra stress placed on her heart when her body went into septic shock during the ten hour wait for treatment. This loss of life could have been prevented had Skylar received the proper medical care in a timely fashion. Since her death, my family has spent countless hours on raising public awareness on the importance of hospital interfacility pediatric transfer agreements and how not having those in place impacted Skylar's short life.

I urge you as a parent or guardian to become more aware of your healthcare facilities and their capacity to treat children's unique health care needs. It is imperative that our children receive the proper medical attention in a timely manner to better improve their chances of survival. I urge you to get involved now before you too fall victim to a lack of system organization as my family did. We lost our precious daughter, but we have vowed to do everything possible to prevent any further loss of life, especially the lives of children. Your advocacy can help save a child's life!

Skylar's Mom
Melanie Jarreau, MBA
Louisiana EMSC
Advisory Council Chair

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Introduction

The Emergency Medical Services for Children (EMSC) National Resource Center (NRC) developed "Getting Started, Staying Involved: An EMSC Toolkit for Family Representatives" to assist parents and caregivers in their efforts to support the EMSC Program at the national and state levels.

The guide contains information about the history of the U.S. emergency medical services (EMS) system. It provides background information about the establishment, current status, and future endeavors of the EMSC Program and its Family Advisory Network (FAN). It addresses the importance of EMSC performance measures and how family representatives contribute to the success of each measure. Most importantly, this guide provides tips on everything needed to help family representatives get started and stay involved in the planning and implementation of state EMSC activities – including maintaining an effective working relationship with the state EMSC project manager, recruiting community partners, and educating legislators.

The NRC wishes all its family representatives the best of luck in their endeavors to address the unmet healthcare needs of our nation's children. We thank you in advance for your extraordinary dedication and commitment. Remember, NRC staff is available to assist you whenever needed. Please contact the Center at (202) 476-4927 or at emscinformation@cnmc.org.

Chapter 1 A History of EMS, EMSC, and FAN

Section I: EMS in the United States

Medical experiences in the Korean and Vietnam Wars provided evidence that survival rates improved dramatically when patients were stabilized in the field and transported immediately to a well-equipped emergency healthcare facility. During the 1960s, civilian medical and surgical communities began to recognize the possibilities of applying these principles to an organized EMS system.

In 1966, Congress passed the Highway Safety Act, paving the way for many localities to begin organizing their own EMS programs with the assistance of the newly founded National Highway Traffic Safety Administration (NHTSA). The Federal government provided funding and additional stimulus for EMS system development through the EMS Systems Act of 1973 (Public Law 93-154).

Early EMS systems were designed to provide rapid intervention for sudden cardiac arrest in adults and rapid transport for motor vehicle crash victims. The medical community, however, failed to recognize that children require specialized care. This knowledge deficit persisted until the late 1970s when pediatricians and pediatric surgeons – identifying poor outcomes among children receiving emergency medical care – became advocates on behalf of their patients. Their goal was to obtain for children the same positive results the EMS system had achieved for adults.

For more information about EMS, read "EMS: Where We Have Been and Where We're Going" available from the National Association of EMTs website at: http://www.naemt.org/aboutEMSAndCareers/history_of_ems.htm.

Section II: EMSC Program

The groundwork for change and improvement in pediatric emergency care was laid in the late 1970s when Calvin Sia, MD, then-president of the Hawaii Medical Association, urged members of the American Academy of Pediatrics (AAP) to develop multifaceted EMS programs that would decrease morbidity and death in children. Dr. Sia worked with U.S. Senator Daniel Inouye (D-Hawaii) and his staff assistant, Patrick DeLeon, PhD, to draft legislation for an initiative on EMS for children.

In 1983, one particular incident served to personalize the need for these services. One of Senator Inouye's senior staff members had an infant daughter who became critically ill. Her treatment demonstrated the average emergency department's (ED) shortcomings when faced with a child in crisis. A year later, U.S. Senators Orrin Hatch (R-Utah) and Lowell Weicker (R-Connecticut) – supported by staff members with disturbing experiences of their own – joined Senator Inouye in sponsoring legislation to establish the EMSC Program. C. Everett Koop, MD, then-Surgeon General of the United States, strongly supported this measure, as did the AAP.

The EMSC Program was established under the Preventive Health Amendments of 1984 (PL 98-555). Administered by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), the Program provides grants to all 50 states, the District of Columbia, and five U.S. territories (Guam, the Commonwealth of the Northern Marianas Islands, Puerto Rico, American Samoa, and the U.S. Virgin Islands). The overall goal is to ensure that all children and adolescents – no matter where they live, attend school, or travel – receive appropriate care in a health emergency.

EMSC Grant Funding Mechanisms

Currently, the Federal EMSC Program funds two types of grants: Targeted Issue and State Partnership. Targeted Issue grants are intended to address specific needs, concerns, or topics in pediatric emergency care that transcend

state boundaries. The primary goal of this grant is to develop and promote a new product or resource. Ideally, promotional efforts should include publication in a peer-reviewed journal.

State Partnership grants fund activities to improve and integrate pediatric emergency care within a state EMS system. The typical applicant is a state government EMS office unless the state decides to delegate the responsibility to an accredited school of medicine. State Partnership grantees are required to include family representation on their EMSC state advisory board. Note that this guide is written specifically for family representatives of EMSC State Partnership grantees.

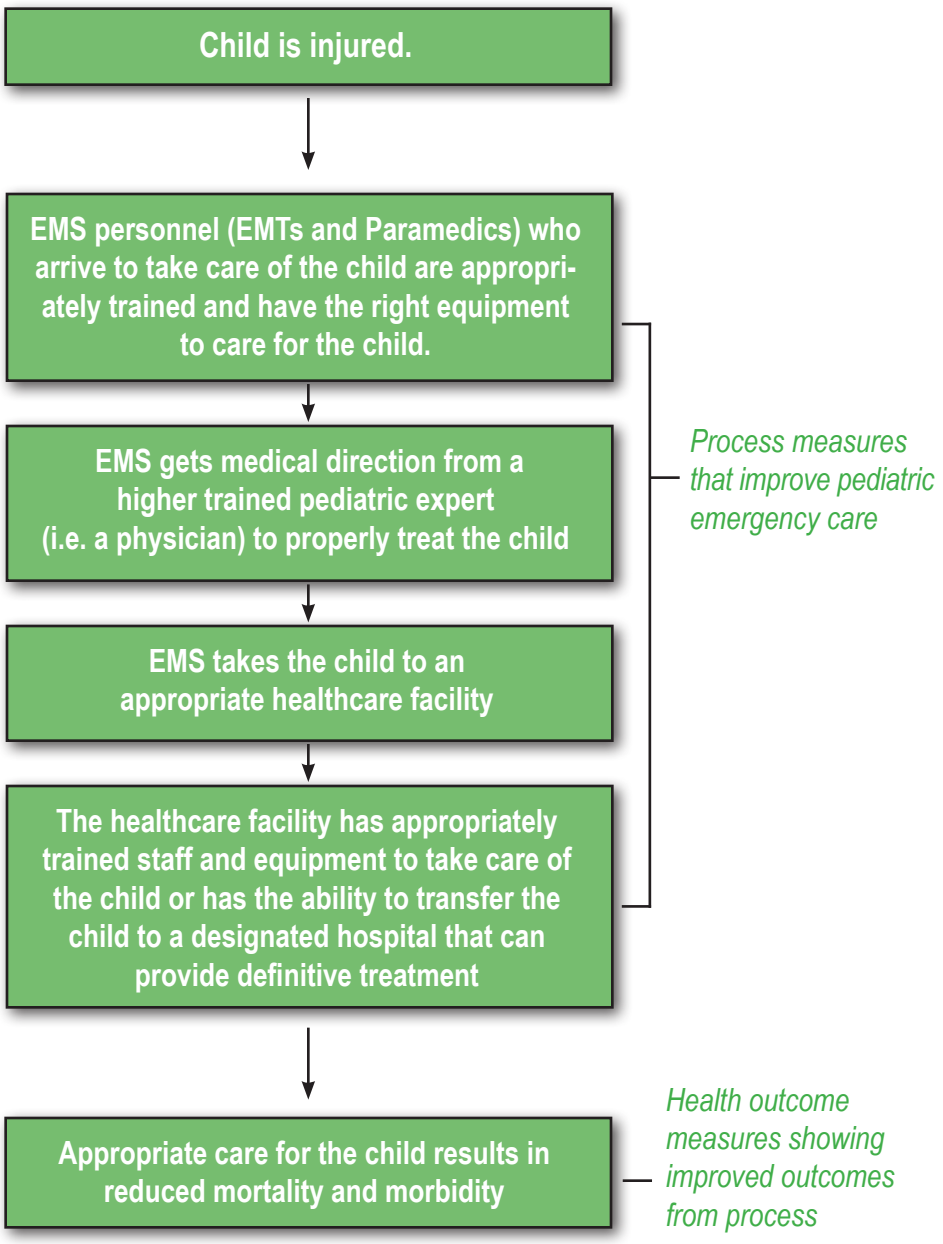
Creation of the EMSC Performance Measures

In 1993, Congress passed the Government Performance Results Act (GPRA) in an effort to hold Federal agencies accountable for achieving results. GPRA requires agencies to develop plans for the objectives they want to achieve, measure their progress towards those objectives, gather information, and communicate their performance to Congress and to the public.

Table 1: Summary of EMSC Performance Measures

Performance Measure 71 (formerly PM 66a (i))	*The percent of pre-hospital provider agencies in the state/territory that have on-line pediatric medical direction available from dispatch through patient transport to a definitive care facility.*
Performance Measure 72 (formerly PM 66a (ii))	*The percent of pre-hospital provider agencies in the state/territory that have off-line pediatric medical direction available from dispatch through patient transport to a definitive care facility.*
Performance Measure 73 (formerly PM 66b)	*The percent of patient care units in the state/territory that have essential pediatric equipment and supplies as outlined in national guidelines.*
Performance Measure 74 (formerly PM 66c medical)	*The percent of hospitals recognized through a statewide, territorial, or regional standardized system that are able to stabilize and/or manage pediatric medical emergencies.*
Performance Measure 75 (formerly PM 66c trauma)	*The percent of hospitals recognized through a statewide, territorial, or regional standardized system that are able to stabilize and/or manage pediatric traumatic emergencies.*
Performance Measure 76 (formerly PM 66d)	*The percentage of hospitals in the state/territory that have written interfacility transfer guidelines that cover pediatric patients and that include pre-defined components of transfer.*
Performance Measure 77 (formerly PM 66e)	*The percent of hospitals in the state/territory that have written interfacility transfer agreements that cover pediatric patients.*
Performance Measure 78 (formerly PM 67)	*The adoption of requirements by the state/territory for pediatric emergency education for license/certification renewal of BLS/ALS providers.*
Performance Measure 79 (formerly PM 68a,b,c)	*The degree to which state/territories have established permanence of EMSC in the state/territory EMS system by establishing an EMSC Advisory Committee, incorporating pediatric representation on the EMS Board, and hiring a full-time EMSC manager.*
Performance Measure 80 (formerly PM 68d)	*The degree to which state/territories have established permanence of EMSC in the state/territory EMS system by integrating EMSC priorities into statutes/regulations.*

Diagram 1: Performance Measures Lead to Improved Care



In 2005, the NRC commenced a two-year endeavor to develop the first set of EMSC performance measures to demonstrate the results of Program funding given to states/territories. To better understand how these measures interrelate and translate to improved pediatric emergency health care, see Diagram 1. Chapter 4 provides a more in-depth description of each performance measure and how family representatives can contribute to the success of each.

In 2006, these measures became the basis for all EMSC State Partnership grants.

Need for Continued EMS System Improvement

The need for comprehensive systems improvement in EMSC is well documented in the Institute of Medicine (IOM) reports related to emergency care. The first IOM report, "Emergency Medical Services for Children," was published in 1993. The report documented a need for: (1) education and training; (2) putting essential tools in place; (3) communication and 911 systems; (4) planning, evaluation, and research; and (5) Federal and state funding.

In 2006, the IOM released the Future of Emergency Care, a series of follow-up reports that included "Emergency Medical Services at the Crossroads," "Hospital Based Emergency Care: At the Breaking Point," and "Emergency Care for Children: Growing Pains." The reports comprehensively described the "fragmented" system of emergency care with emphasis in the pediatric report on the "uneven" nature of emergency care for children. Key recommendations from this report include: (1) improve coordination of care, (2) regionalize specialty pediatric medical care, (3) increase accountability, (4) arm the emergency care workforce with pediatric knowledge and skills, (5) enhance patient safety advancements in technology and information systems, (6) improve emergency preparedness for children involved in disasters, and (7) build an evidence base for pediatric emergency care.

The 2006 report reiterated findings from the original EMSC IOM report, which stated that "children who are ill or injured have different physical and psychological needs than adults with the same problems. Children have different heart rates, blood pressures, and respiratory rates, and these vital signs change as they grow. Children often need equipment that is smaller than what is used for adults, and require medication in doses carefully calculated according to their weight. Children

have special emotional needs as well, often reacting very differently to an injury or illness than adults do."

Section III: Family Advisory Network

In 1999, the NRC created the Family Advisory Network (FAN) to facilitate the inclusion of family representatives into state EMSC programs. To assist with this process, the NRC provides the following services/resources to its FAN membership:

- technical assistance related to family involvement strategies, advocacy, and family-centered care;
- publications, such as this guide, that serve as useful tools for professional development;
- educational opportunities, such as comprehensive workshops on family-centered care conducted at the Annual EMSC Grantee Meeting;
- vehicles for communicating, such as the semi-annual newsletter *FANMail* and the FAN listserv;
- a section on the NRC website designed to provide the most up-to-date contact information on other state EMSC family representatives; and
- a forum to acknowledge family representatives who have provided meritorious service in the emergency medical needs of children. The National EMSC Heroes Award for "Parent Volunteer of the Year" is presented annually at the Annual EMSC Grantee Meeting.

What Is SNAP?

The Special Needs Alert Program (SNAP) is a pre-hospital notification program for any child who has special emergency care needs. When a child is registered in this program, EMS providers in the state of Delaware are alerted to the child's complete medical history. The prior knowledge of the medical history enables first responders to provide appropriate emergency care for the child and reduces the level of stress usually experienced by the family when the need for prehospital care is sought. SNAP enables families to meet with EMS personnel in the family's home before they have to make a 911 call. For more information about the program, call (302) 744-5415.


FAN Mail

EMSC Family Advisory Network Newsletter

Fall 2007 Issue

The Safe Baby: An EMSC National Resource Center Interview with Safety Expert Debra Holtzman

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Helpful FAN Resources

In September 2007, the EMSC National Resource Center (NRC) interviewed internationally recognized safety and health expert and award-winning author Debra Holtzman, JD, MA. Her books, *The Panic-Proof Parent* (McGraw-Hill, 2000) and *The Safe Baby: A Do-It-Yourself Guide to Home Safety* (Sentient Publications, 2005) have received rave reviews and endorsements by leading parenting authorities and safety and health organizations. *The Safe Baby* won the National Parenting Publications' Gold Award, one of the country's most authoritative consumer-awards recognizing the best in children's and parenting resources.

Debra has been featured on hundreds of radio and television shows, as well as in *Newsweek*, *Parenting*, *Child*, *Us Weekly*, *Woman's World*, *Family Circle*, *Boston Globe*, *Chicago Tribune*, *Chicago Sun-Times*, UPI, and the *Washington Times* to name a few.

For the past 11 years, she has volunteered with the Broward County (FL)

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Debra Holtzman

2007 EMSC Family Representative Volunteer of the Year: Shauna Hatton-Ward

Congratulations to Shauna Hatton-Ward, this year's recipient of the EMSC Family Representative Volunteer of the Year award. Shauna received her award on June 19, during a special National Heroes Award event held in conjunction with the 2007 Annual EMSC Grantee Meeting in Silver Spring, MD.

Shauna's expertise in caring for and understanding the needs of children in emergency situations began with the birth of her daughter, Amberlee, 24 years ago. Amberlee experienced an anoxic event at birth that resulted in severe cerebral palsy. Amberlee's life of medical complications has provided Shauna the experience that enhances and enlightens her perspective regarding family-centered medical care.

From 1995 to 2000, Shauna was the Parent Support Coordinator in the NICU at Primary Children's Medical Center in Salt Lake City, Utah. Shauna was instru-

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Today, the FAN membership includes family representatives from 52 states/territories. As of July 2009, nine states/territories had more than one state family representative. FAN members contribute to their state program activities in numerous ways, including, but not limited to: serving as members, chairs, and co-chairs of their state EMSC advisory committee; coordinating special community outreach projects, such as the Special Needs Alert Program (SNAP) in Delaware (see box above); assisting with the development and implementation of EMSC policy objectives; and helping to plan, present, and promote educational offerings within their state.

Family representatives are also involved at the national level. Several FAN members sit on the Federal EMSC Strategic Planning Committee; others are involved on the Annual EMSC Grantee Meeting Planning Committee. In addition, members serve as contributing writers for *FANMail*, a semi-annual newsletter distributed by the NRC to the FAN membership. They also share resources and information through the NRC-moderated FAN listserv and through the weekly electronic news digest *EMSC QuickNews*.

Chapter 2 What Is A Family Representative?

Family representatives are individuals selected by the state EMSC advisory committee and/or the state EMSC project manager to represent the needs of families in the community. The state EMSC advisory committee guides state EMSC grantees toward meeting the EMSC performance measures. Members of the EMSC advisory committee assist grantees in strategic planning, obtaining buy-in from the state/Territory leadership to effect system change, and assure that family issues are not overlooked. The state EMSC project manager is the person responsible for the day-to-day grant activities.

Section I: Qualifications and Criteria

Qualifications to be a family representative, if any, are determined by the state EMSC program. The basic standard for recruiting and selecting a family representative is to identify a parent from the community who is interested in improving the health care system for their child. An EMSC family representative is usually a leader in the community who exemplifies volunteerism.

Becoming an EMSC family representative does not require an individual to have a background in EMS. However, the role does require that the individual be passionate about the healthcare needs of children and have some knowledge about the EMS system within their local community. This knowledge may be based on a personal experience or that of someone close to them. Knowledge of the local EMS system is necessary in order to provide a consumer's perspective during EMSC program planning, development, and implementation – particularly when developing patient- and family-centered systems of care.

Often a state's EMSC advisory committee or the EMSC project manager will choose a family representative based primarily on his/her willingness to dedicate their time and share their knowledge. Current EMSC family representatives have diverse backgrounds and expertise; for example, some are homemakers, consultants, teachers, or students.

When selecting a state EMSC family representative, the NRC recommends that the individual be:

1. a parent, legal guardian, or caregiver;
2. willing to learn and become familiar with the local, state, and national EMS system, as well as the EMSC Program through orientation and training;
3. able to commit time and effort to the project for at least one year; and
4. able to tactfully and professionally communicate and is reflective when listening to issues regarding emergency care and children.

Section II: Guidelines for Assisting the Program

The NRC strongly encourages all family representatives to communicate with the NRC as often as needed. Whether seeking resources or trying to stay informed of Federal Program progress, the NRC is always available to support family repre-

sentative efforts. In turn, the NRC will ensure that timely updates on program activities are distributed on a regular basis via the FAN Listserv. Note that it is the family representative's responsibility to notify the NRC of any changes in contact information. This can be done by calling (202) 476-4927.

In addition to maintaining two-way communication with the NRC, state EMSC family representative are required to:

1. communicate regularly with their state EMSC project manager;
2. commit their time and effort to the state project for at least one year;
3. represent their state EMSC project at EMSC-related functions during the calendar year;
4. be professional, courteous, open, and honest in communications and in performance of advocacy-related activities;
5. value the worth of each individual and recognize that everyone contributes to the success of the state project and organization; and
6. enjoy the adventure of being a part of EMSC and have fun!

On the other hand, state EMSC family representatives may not:

1. use the state EMSC Program for personal or non-professional goals; and
2. disclose matters of a confidential nature.

Section III: Role of State EMSC Project Managers

State EMSC project managers are encouraged to maintain contact with their family representative on a weekly basis, if possible. In addition, state EMSC project managers are required to conduct an orientation for new family representatives. This orientation should include an explanation of the following:

1. current EMSC project opportunities;
2. possible tasks the family representative may want to be involved in based on his/her expertise and knowledge;
3. amount of time commitment expected and/or needed from the family representative; and
4. the process for volunteering for upcoming activities.

Section IV: Importance of Family Representatives

Families are a valuable resource in the planning, development, and evaluation of prehospital and acute care services for children. They impart a consumer's perspective and serve as community allies in support of patient- and family-centered health services throughout the entire continuum of care. Thus, the EMSC Program encourages family involvement in all aspects of program development and requires every EMSC State Partnership grantee to recruit a family representative to assist with state efforts to achieve the EMSC performance measures. The role of families specific to the EMSC performance measures is found in Chapter 4.

Active involvement of parent representatives improves the integration of family-centered care into state EMSC

initiatives. Family-centered care is a structured process of managing a patient's healthcare characterized by the mutually beneficial collaboration between patient, family, and health professionals. It is a direct reflection of one of the most important changes in our health care system in recent years – the expectation that consumers will be involved not only in their own care, but also in the design and modification of health care systems. This structured process of caring for a patient also acknowledges the expertise and range of experiences families bring to the healthcare system. From an EMSC perspective, family-centered care acknowledges that families are the constant in their child's life and that they bring important strengths to their child's health care experiences.

Some of the many benefits of family-centered care include:

- improved medical and developmental outcomes for children;
- clinics, hospitals, private practices, health care agencies, and providers that are more sensitive and responsive to patient and family needs and priorities;
- reduced health care costs;
- better use of scarce resources;
- enhanced patient and family satisfaction, as well as provider satisfaction; and
- a cadre of families capable of advocating for resources to improve the delivery and quality of health care.

As consumers of the EMS system, family representatives can make positive contributions in such areas as:

- improving direct patient care;
- designing and evaluating programs and systems;
- organizational governance;
- supporting public policy and fundraising activities; and
- raising public awareness about specific issues.

At the national level, the EMSC Program has consistently sought out opportunities to promote and develop family-centered care principles by incorporating comprehensive workshops and sessions on family-centered care at the Annual EMSC Grantee Meeting; creating the National Heroes Award for "EMSC Parent Volunteer of the Year;" and ensuring family representation on national committees and taskforces.

The contributions that a family representative makes is based on the needs of their state's EMSC project and the skills and experience they bring to the program. Some family-centered activities that representatives are involved in include: media advocacy; policy development; task force, committee, and advisory board participation; internet/web projects; needs assessments; and community events. Family representatives will need to work with the state EMSC project manager to match their skills and interest areas with the needs of the state.

Chapter 3 Getting Started and Staying Involved

Section I: Attending EMSC Advisory Committee Meetings

Participation in state EMSC advisory committee meetings is critical as it facilitates growth and understanding of the political process and identifies the challenges state programs must work through to reach their goals.

The parent representative plays a very important role on the advisory committee. He or she provides the reality check of what the consumer would like and need from the EMS system. Many parent representatives have children with special health care needs and are therefore familiar with the unique needs of children requiring frequent utilization of the health care system and the challenges imposed by the emergency care system.

Further, as a community member, family representatives are in the unique position of being able to take legislative/regulatory action. Other members of the committee, particularly government employees, cannot participate in these activities. This makes family representatives one of the most effective members of the advisory group.

Section II: Maintaining Regular Contact with the EMSC Project Manager

To a large extent, family representatives provide support to the EMSC project manager. Since EMSC advisory committees meet at a minimum quarterly, this forum alone does not adequately meet the on-going, supportive needs of the EMSC project manager. It is therefore recommended that family representatives and project managers maintain a more frequent schedule of communication; weekly meetings or conference calls are advisable. Frequent meetings or telephone calls facilitate:

- better knowledge of the Federal EMSC Program, the state EMSC project, and their respective goals;
- more in-depth discussions on the status of performance measure activities and assistance a family representative might provide;
- disclosure of challenges experienced or expected by the EMSC manager and discussion on how family representatives may be of assistance;
- clarification of EMS system operations or hospital processes potentially impacting a measure's success;
- discussion of advisory committee challenges and the role the family representative might play in assuring advisory committee buy-in of the performance measures and in maintaining group cohesiveness as strategies are developed to achieve the measures;
- identification of community groups that may be of value in strengthening the state EMSC project;
- an opportunity to reconfirm the value of work being pursued by the committee and the state EMSC project;
- better understanding of the role and needs of families in an emergency situation; and
- the development of plans to enhance education regarding the Federal and state EMSC programs, emergency care needs of children, and the EMSC performance measures.

The relationship between a family representative and a project manager often can be described as a true partnership; both benefit from the collaboration. The manager develops a better understanding of how emergencies impact children and families. The manager also receives gratuitous support to carry out strategies designed to achieve the EMSC performance measures. The family representative benefits by ensuring that the unique emergency care needs of his/her child are integrated into the system.

Section III: Participating in Various Activities, Events, and Meetings

It is fairly easy to remain actively involved in the state EMSC project by simply attending the advisory committee meetings, providing feedback when needed, and working on assigned EMSC project activities. However, keep in mind that most state EMSC project managers have limited to no additional staff and thus rely heavily on their family representative. To add value to a state EMSC project, family representatives should involve themselves in the following meetings, activities, and events:

- attend the Annual EMSC Grantee Meeting;
- review state EMS rules, regulations, protocols, and other publications related to healthcare legislation or patient- and family-centered care;
- recruit and determine the roles other parents can fill to help increase the visibility of EMSC in the state;
- identify and secure organizational partners (see "Building Coalitions and Establishing Community Partners" for more information);
- participate in public education campaigns and other community activities – such as community fairs, school functions, and church bazaars – that provide opportunities to promote the activities of the state EMSC project;
- contact other EMSC state family representatives to learn about the effective strategies they have used to assist state EMSC programs in reaching their goals (see the NRC website for a list of family representatives by state);
- communicate regularly with the NRC to ensure receipt of patient- and family- centered care resources; and
- visit the NRC website each week to stay informed of the latest EMSC news.

Family representatives have also been active in fundraising events, such as bake sales and raffles. The funds raised have been used to purchase pediatric equipment and supplies and could be used to cover the cost of advisory committee meetings and annual state EMSC meetings, if available.

Several state EMSC projects have developed fact sheets (see Appendix A: Example Colorado and Idaho EMSC Fact Sheets), flyers, brochures, and posters to promote their activities. Consider working with the state project manager to distribute these resources to professional organizations, the media, the general public, and policymakers.

Keep in mind, family representatives play an important role in the development of resources. For example, family representative should ask that the resources include their personal experiences with the EMS system. Sharing such real-life experiences is a compelling way to convince others that EMSC is needed in the community.

Section IV: Building Coalitions and Establishing Community Partners

"Coalition building is the ongoing process of cultivating and maintaining relationships with a diverse network of individuals and organizations who share a common set of principles and values. These individuals and organizations, united by a common mission or cause, agree to collaborate, to work with one another, to achieve results they are more likely to achieve together than alone." (Winer and Ray, pg. 24)

Coalitions within the EMSC Program are networks of support that are broader than state advisory boards and committees: they encompass both the formal and informal relationships of support and involvement. Coalitions include the many "friends" of the state EMSC project who contribute in some way to its success, no matter how small the contribution may be.

EMSC family representatives play a critical role in coalition building. They are one of the key members of the EMSC advisory committee that connect the project manager to the community. Many family representatives are already members of or actively involved in a variety of community- and civic-based organizations, such as: the Lions Club; the

Rotary Club; the Parent-Teacher Association; Boys/Girls Scouts of America; and/or the local chapters of Easter Seals, Family Voices, Kiwanis International, the General Federation of Women's Clubs, the Federation for Children with Special Healthcare Needs, or any other organization that shares an interest in children or health care. Due to family health circumstances, some family representatives may also have established relationships with EMS services, hospitals, durable medical equipment suppliers, and the like.

Family representatives can help build coalitions by sharing these contacts with the EMSC advisory committee and the EMSC project manager. By introducing the EMSC project manager and the advisory committee to other community and healthcare leaders, essential resources and support needed to bring about system change may be realized.

Although many coalition members may not be able to donate a substantial amount of time to EMSC, they may be able to provide free or inexpensive program resources that have already been developed. For example, Safe Kids Worldwide (http://www.safekids.org) may lend out slides or donate public education materials. A helmet manufacturer or distributor may contribute bike helmets at a reduced cost. A children's hospital may contribute training materials and equipment. A rehabilitation facility may share data reports demonstrating the cost of providing patient care.

Sharing their products and resources is just one way in which community partners can contribute to the state EMSC project. Other ideas include asking partners to publish a story in their organizational newsletter, post information to their website, or distribute messages through their listservs. Consider asking partners to introduce the state project manager to their key contacts in the media, to state policymakers who support healthcare and child well-being initiatives, and to fundraising allies that have supported causes similar to EMSC. Greater visibility among these groups may generate new political, financial, and programmatic support for the project.

In addition, coalition members can help educate public policymakers or administrators about the need to make improvements in the emergency system of care for children and the need for the states EMSC project in particular. To ensure this is done without violating restrictions against lobbying, refer to Chapter 5: The Legislative Process for guidance.

Utilizing the resources, services, and expertise of others will save the state EMSC project time, money and energy, and will help to build enthusiasm and support for the project. It is a way to validate the work that others have done and to recognize them as a resource.

Chapter 4 Achieving EMSC Performance Measures

The EMSC Program has developed and is expecting all EMSC State Partnership grantees to achieve defined performance measures (see "Creation of EMSC Performance Measures," page 10, for a brief explanation of the EMSC Performance Measures). These measures steer all grantees toward a common goal of better pediatric emergency care.

This chapter will clarify each performance measure and explain a family representative's role in moving the measure forward. Keep in mind, that a family representative's personal experiences with the EMS system provide a pathway to reach health care professionals, the general public, and public officials. Note that many of the terms referred to in this chapter (i.e., BLS and ALS providers, patient care units, facility recognition, etc) are defined in Appendix B: Frequently Used Terms and Acronyms in EMSC.

Section I: Pediatric Medical Control

Overview of the Performance Measure	*Why Is This Important?*
Ensure the operational capacity of the State EMS system to provide pediatric emergency care by ensuring prehospital provider agencies have on-line and off-line pediatric medical direction at the scene of an emergency for BLS and ALS providers.	Children are not little adults. Without appropriate pediatric medical direction, a prehospital provider could underestimate the pediatric patient's condition, make a medication dosing error, or be incapable of effectively triaging multiple pediatric patients.

Family Representative Role

If off-line (i.e., written) protocols already exist in the state, family representatives should review each to determine whether patient- and family-centered care procedures and policies are included. An explanation of family-centered care systems is included in Chapter 2, Section IV. If written protocols are not in place, family representatives can contribute to their development by providing feedback on the importance of ensuring that all EMS providers follow specific procedures that keep a family appraised of their child's medical condition.

Note that family representatives are not expected to be familiar with the medical terminology within the pediatric protocols.

Section II: Pediatric Equipment and Supplies

Overview of the Performance Measure	*Why Is This Important?*
BLS and ALS patient care units in the State/Territory will have the essential pediatric equipment and supplies, as outlined in national guidelines.	Children come in different sizes. Without the right sized pediatric equipment, a pediatric airway cannot be managed, an IV cannot be established, a cervical spine (c-spine) cannot be immobilized, and appropriate medication doses cannot be delivered.

Family Representative Role

A family representative can help to ensure all patient care units responding to a 911 call have the pediatric equipment and supplies needed to save the life of a child. First, talk with the state's EMSC project manager to find out what equipment and supplies the patient care units in the state have and what equipment is missing. Second, work with the project manager to determine what can be done locally to ensure all the equipment and supplies are available on the units.

Partnership development is one strategy grantees have used with great success to help meet this performance measure. For example, the Indiana EMSC program partnered with the Indiana District of Kiwanis through its Young Children Priority One (YCPO) initiative to provide pediatric equipment bags to more than 32 counties in the state. In recognition for its support, the Indiana District of Kiwanis received a 2001 EMSC National Heroes Award for Community Partnership of Excellence.

Since 2000, the Nebraska/Iowa Kiwanis Foundation has partnered with the EMSC Program to provide needed basic level pediatric equipment and education to EMS services in Nebraska and Iowa. In 2005, the General Federation of Women's Clubs' Oconomowoc (WI) Junior Woman's Club (OJWC) worked with the Wisconsin EMSC state project to distribute the Broselow-Luten tape to all 32 fire departments in Waukesha County. Thanks to a $24,000 grant OJWC received from a private foundation, all Waukesba County ambulances now also have ALS and BLS pediatric bags.

Partnering with local civic and community-based organizations is ideal. These types of organizations often make donations to benefit the unmet needs of the community, such as purchasing pediatric medical equipment. For more information on partnership development, see Chapter 3, Section IV, "Building Coalitions and Establishing Community Partners."

Section III: Hospital Recognition

Overview of the Performance Measure	*Why Is This Important?*
Establish a statewide, territorial, or regional standardized system that recognizes hospitals that are able to stabilize and/or manage pediatric medical emergencies and trauma.	Without a pediatric emergency healthcare facility recognition process, access to appropriate critical care, trauma care, or burn care could be delayed. Delays can result in negative patient outcomes.

Family Representative Role

Family representatives can help to ensure the establishment of a statewide, territorial, or regional standardized system that recognizes hospitals by their capability to stabilize and/or manage pediatric medical emergencies and trauma. Talk with the EMSC project manager to find out whether a standardized system exists. If so, ask what hospitals have been designated, which have not, and why. If a system does not exist, learn more about the importance of a recognition system – especially its affect on EMS providers – then work with the state EMSC advisory committee to develop a system. As a parent/guardian, it is important to know which hospitals in the state are capable of managing pediatric emergencies and trauma. If the system merely directs pediatric emergencies to the closest hospital regardless of its capacity to care for children and their unique needs, timely access to urgent specialized care may be jeopardized.

Section IV: Transfer Agreements and Guidelines

Overview of the Performance Measure	*Why Is This Important?*
Hospitals in the State/Territory will have written pediatric interfacility transfer agreements and guidelines.	The most severely ill and injured children sometimes require specialized care that is only available in select hospitals. Without effective interfacility transfer agreements and guidelines, the timely and appropriate transfer of patients to the right level of emergency care is placed in jeopardy. These delays could result in negative patient outcomes.

Family Representative Role

Health insurance status and other factors, such as a receiving hospital's patient capacity, often prevent the immediate transfer of a patient to an institution equipped to provide specialty medical treatment. Family representatives can help ensure timely patient transfers by working with their state's EMSC advisory committee and project manager to ensure all hospitals in the state have interfacility transfer agreements and guidelines in place. Talk with the project manager to determine if

interfacility transfer agreements and guidelines exist and whether they are in place with all hospitals in the state. Learn how to work with the hospitals and review the current interfacility guidelines to ensure patient- and family- centered procedures are incorporated during transfers.

Section V: Pediatric Training of Prehospital Providers

Overview of the Performance Measure	*Why Is This Important?*
States/Territories will adopt requirements for pediatric emergency education prior to recertification of BLS and ALS providers.	Nationally, 10% of ambulance emergency runs are for sick or injured children. It is estimated that of that 10%, only one-tenth of the cases are for critically ill and/or injured children. Information gained from national surveys show that, due to their limited exposure to pediatric emergencies, most prehospital providers often feel inadequate and poorly prepared to provide care to children. Continuing education helps ensure that prehospital providers are ready to take care of a pediatric patient in the field. Continuing education also improves the quality and effectiveness of pediatric emergency care, and thereby, improves pediatric outcomes (e.g., reduced morbidity and mortality).

Family Representative Role

Family representatives can help ensure all EMS providers receive pediatric training before they are recertified/relicensed in the state. Talk with the EMSC project manager to learn whether pediatric education is a standard requirement prior to recertification. Determine the type of pediatric training received and how often. Should pediatric training not be required, strategize with the EMSC project manager in partnership with the state EMSC advisory committee to combat existing barriers. Discuss the challenges and determine how family representatives can help.

Ask the project manager whether a family representative can contact the local EMS agencies to discuss their pediatric training programs and determine the issues that prevent the EMS agency from providing and requiring pediatric education prior to recertification. After identifying the issues, work with the state advisory committee to strategize solutions.

Section VI: EMSC Permanence

Overview of the Performance Measure	*Why Is This Important?*
Permanence of the EMSC Program will be established in the State/Territory EMS system.	Integration of pediatric priorities into existing EMS rules and regulations ensures that your EMS system changes will be permanent. An EMSC Program that has permanence includes a dynamic advisory committee, pediatric representation on the State EMS Board, and a full-time EMSC project manager. These components will lead to successful EMS improvements for pediatric patients should the Federal EMSC grant program end.

Family Representative Role

The preceding performance measures must be adopted and integrated into state statute or regulation. A family representative is in a position to educate state policymakers regarding the importance of the state EMSC project's initiatives and the performance measures. In particular, a family representative may want to share with the policymaker his/her personal experiences with the EMS system; sharing such real-life experiences reminds others about the importance of EMSC in the community. For more information on the legislative process and a family representative's involvement in it, see Chapter 5.

Chapter 5 The Legislative Process

Section I: Federal Legislative and Regulatory Process

Federal Legislative Process

The U.S. Congress, which is comprised of the U.S. House of Representatives and the U.S. Senate, plays an important role in ensuring the continued existence of the EMSC Program. It is responsible for the Program's authorization and annual Federal appropriations. To understand the Federal legislative process, it is important to understand the following two terms: authorizing legislation and federal appropriations.

Authorizing Legislation. Authorizing legislation establishes a Federal agency or program and sets a general funding level for the agency or program, but does not provide funding itself. Authorizing legislation not only establishes a program in name, but it also delineates in statute what a program is allowed to do and what it is not allowed to do. This is often referred to as a program's scope of authority. For example, the legislation authorizing the EMSC Program defines the entities eligible to receive EMSC grants (states/territories or academic medical centers), the duration of each grant, and how many EMSC grants a given state may receive at one time.

Federal programs are usually authorized to exist for a finite amount of time, typically three to five years, at which time Congress must renew the program's authorization through the legislative process. As such, the EMSC Program must be renewed by Congress every few years. This is commonly referred to as "reauthorization." Congress can make changes to a program's scope of authority when it is reauthorized.

For information on how a bill becomes a law, see Appendix C.

Federal Appropriations. While authorizing legislation sets general funding levels for Federal agencies and programs, an indicator of how much funding Congress thinks the program should receive, it does not provide funding itself. Actual program funding is accomplished through the Federal budget and appropriations process.

Congress must complete the budget and appropriations process each Federal fiscal year (October 1 through September 30). This means that, as a general rule, Federal agencies and programs receive funding one year at a time. The amount of funding a program receives can change from year to year, depending upon how much money Congress decides to allocate to it. Based upon Federal policy and budget priorities, a program may receive a funding increase, a funding decrease, or level funding.

In theory, Federal agencies and programs must be authorized in order to receive an annual appropriation. In practice, however, Congress regularly appropriates funding to programs whose authorization has expired. It may take Congress several years to reauthorize a program through the legislative process; during this time, Congress often chooses to continue funding the program, despite the fact that its authorization has lapsed.

If, however, all of the appropriations bills are not signed into law by the beginning of the fiscal year on October 1, Congress may pass a continuing resolution (CR). A CR funds agencies and programs, usually at the previous year's level, for a defined amount of time or until the appropriations bills are enacted.

For more information on the Federal budget and appropriations process, see Appendix D.

Federal Regulatory Process

Complementing the Federal legislative process is the Federal regulatory process. Congress sometimes passes laws that purposefully lack detail, instead leaving it to the various executive branch agencies to issue rules and regulations defining how the laws are to be put into practice. For example, Congress may pass a law giving the Department of Health and Human Services broad authority to improve vision care for newborns; the Department then drafts specific initiatives to improve such care.

Executive agencies publish proposed regulations in the Federal Register and allow for a public comment period. At the end of that period, an agency will consider the comments and publish a final regulation on the issue. Note that Congress can overturn a regulation through the legislative process within 60 days of it being made final.

Section II: State Legislative and Regulatory Process

State governments function similarly to the Federal government, operating with legislative, executive, and judicial branches; the former two are most important in supporting a state's EMSC Program. The activities of these branches, however, are regulated by a state constitution and therefore differ from state to state. While general information on state legislative and executive branches is outlined below, family representatives may want to speak with their EMSC project manager for more information on a state's specific legislative processes.

Legislative Branch

All states but one have legislatures that are bicameral or consist or two chambers: the House, sometimes referred to as the Assembly, and the Senate. Legislators may be called representatives, delegates, assemblymen and assemblywoman, or senators. Only Nebraska's legislature is unicameral, consisting of one chamber with all members referred to as senators.

States follow a legislative process very similar to the Federal process. Legislators introduce bills, which are then referred to and considered by a relevant committee. After committee approval, the bill must be considered by both legislative chambers. If both chambers pass the same version of the bill, it is presented to the governor.

Executive Branch

The executive branch is run by a governor, who, as the chief executive officer of the state government, oversees numerous agencies, commissions, and boards. As with the Federal system, state legislation is approved or vetoed by the Governor.

The executive branch also oversees the state regulatory process. As with the Federal legislature, state legislatures sometimes pass laws that are purposefully lacking in detail, leaving it to the state's various executive branch agencies to come up with the specifics of the law through rules and regulations. For example, a state legislature may pass a law giving the state's Department of Health broad authority to improve vision care for newborns; the department then drafts specific initiatives to improve such care.

Executive agencies publish proposed regulations in a public document, sometimes called a register or administrative bulletin, and allow for a public comment period. At the end of that period, an agency will consider the comments and publish a final regulation on the issue. Note that many state legislatures can act to overturn a regulation through the legislative process.

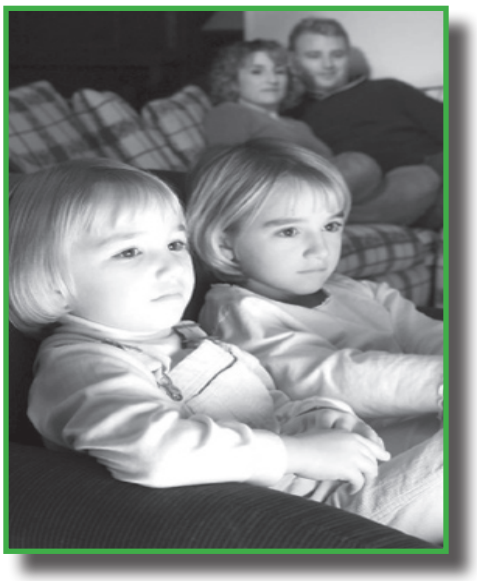
Section III: Educating and Informing

A family representative may be able to educate state and Federal policymakers regarding the importance of an EMSC project's initiatives. Family representatives can make a difference by sharing their personal experience with the EMS system, if they have one. They may explain the importance of the EMSC performance measures in ensuring all children receive the highest quality medical care when they are ill or injured, whether they are home or traveling to another state.

Before taking on any activities to educate policymakers, be sure to work with the EMSC project manager to craft a message. If a family representative plans to identify him/herself with their employer or as a member of a particular professional organization (e.g., Family Voices or the Parent-Teacher Association) while speaking to a state or Federal policymaker, be

sure to notify the employer or organization. They will make sure the legislative activities do not conflict with their rules and priorities.

To increase the impact of a message, consider visiting the policymaker as part of a group; fellow state EMSC advisory committee members may be willing, and able, to assist in these efforts and will add additional viewpoints. Again, before organizing such a group effort, be sure to consult with the EMSC project manager.



Additional tips to help educate state and Federal policymakers include:

- Frequently, family representatives will meet with an aide and not the legislator. It is important to educate the staff member because he/she will, in turn, educate the legislator.
- Before the visit, learn about the legislator (e.g., party affiliation, committee assignments, legislative interests, and personal or professional affiliations).
- Plan what to say in advance and keep the message simple, direct, and brief.
- If organizing a group visit, designate a chief spokesperson and an order of speaking. Ensure that everyone in the group has a role in the effort by planning in advance what each person will say. Avoid repeating the same information.
- Provide the legislator or aide with a fact sheet on the state's EMSC grant activities (see Appendix A: Example Fact Sheet from Colorado and Idaho EMSC.)

- Be prompt – a few minutes early, if possible.
- Prepare a condensed version of key discussion points in case the meeting gets cut short;
- Don't assume that the legislator or aide is familiar with EMSC activities. Remember, you are the expert;
- Explain to the legislator or his/her aide what EMSC means to you, your family, and your community.
- Leave contact information or a business card.
- After the visit, write a thank-you note, and follow-up with requested information.

For more information on speaking to state and Federal policymakers, contact the NRC's senior public policy and partnerships specialist at (202) 476-4927.

Chapter 6 Essential EMSC Resources

Section I: EMSC National Resource Center

The EMSC National Resource Center was established in 1991 to help improve the pediatric emergency care infrastructure throughout all 50 states, the District of Columbia, and the territories. The Center is housed within Children's National Medical Center, one of America's leading pediatric institutions serving sick and injured children.

The NRC supports the Federal EMSC Program and its state grantees by identifying resources and providing technical assistance. Specifically, the NRC provides guidance in project management, identification of resources and model programs, grant writing, grant management, strategic planning, implementation of performance measures, and the training or prehospital and acute care providers.

The NRC also hosts the website http://www.childrenshospital.com/emscnrc, which offers public information about the national effort. It also features What's New at EMSC, an e-journal featuring the latest news and findings in the pediatric health care community, and the NRC Toolboxes, a collection of information and resources on a specific topic currently of interest to the EMSC community. To learn more about each state/Territory's EMSC project and its family representative(s), visit the site today.

In addition, the NRC runs five listservs (the EMSC Grantee Listserv, the Pediatric Emergency Care Applied Research Network (PECARN) Listserv, the Research Listserv, the Family Advisory Network Listserv, and the PECARN Public Relations Listserv), plans the Annual EMSC Grantee Meeting, manages the EMSC Grantee Product database, and oversees the Family Advisory Network.

Section II: EMSC Webcasts

The EMSC Program frequently conducts webcasts to educate others about Federal Program priorities. To view the webcasts, go to: http://www.mchcom.com. Once here, click on "Archived Webcasts" then "EMSC Webcasts." The webcast "EMSC State Partnership Performance Measures" held December 4, 2007, will provide family representatives with additional information about the EMSC performance measures. Another webcast of interest is "Family-centered Care and the Role of EMSC Family Representative." View this webcast to gain additional insight about the Federal Program and to learn about creative ideas for family representatives to get started and stay involved in their state's EMSC project.

Section III: EMSC-related Resources

The NRC maintains a complete list of reading resources for its FAN membership. Listed below are a few of those resources considered "must reads." Each resource listed is available on line at no cost or for a nominal fee. Appendix E, see page 39, lists a variety of websites and resources that may be of interest to family representatives.

A family-centered approach to planning and measuring the outcome of interventions for children with attention-deficit/hyperactivity disorder.

Ambul Pediatr. 2007 Jan-Feb;7(1 Suppl):60-72. Review.
Cunningham CE.

Family-centered care seeks to create an environment that entails the physical, emotional, developmental, and social needs of children and has been a primary objective of many family advocates in the last decade. Family-centered care aims to provide support between the family and their child's healthcare provider. The fundamental goal is to ensure the planning, delivery, and evaluation of a healthcare system that is built upon an active participation between families and professionals. This article takes into consideration parenting and family factors, which are utilized when planning and measuring the outcome of interventions for children with attention-deficit/hyperactivity disorder (ADHD). Some of the measures looked at

include: parenting and parent-child relationships, parental cognitions, parental adjustments, marital interactions, general family relationships, and adaptive child functioning within the family. All measures are reviewed in depth to acknowledge how important family activities influence the overall development and treatment of a child with ADHD.

The family-centered approach establishes better health outcomes, wiser allocation of resources, as well as greater patient and family satisfaction.

PMID: 17261485
The many roles of families in "family-centered care"—part IV.
Pediatr Nurs. 2007 May-Jun;33(3):263-5.
Landis M.

A parent whose premature twins were cared for at Children's Hospitals and Clinics of Minnesota describes giving back to the hospital as a member of the Hospital's Family Advisory Council. Members of the Council assist the administration in developing, implementing, and evaluating the services and the facilities of the hospital system and have input into hospital policies and initiatives. Members also educate hospital leadership, staff, managers, students, and new employees about the needs of families and how care can be improved. In addition, Family Advisory Council members interact with other patients and families by fielding concerns and suggestions. Children's Hospitals and Clinics of Minnesota have a strong commitment to involving family members as advisors in every aspect of health care and on every level of the hospital system.
PMID: 17708186

Family presence during pediatric trauma team activation: an assessment of a structured program.

Pediatrics. 2007 Sep;120(3):e565-74.
O'Connell KJ, Farah MM, Spandorfer P, Zorc JJ.

This prospective study suggests that there is an overall low prevalence of negative outcomes associated with family presence during pediatric trauma team evaluation after implementation of a structured family presence program. Excluding family members as a routine because of provider concerns about negative impact on clinical care does not seem to be indicated.

A total of 197 family members participated in this study. There were no cases of interference with medical care by family members. Seven family members were asked to leave the trauma area by staff after initiation of family presence for various reasons. Times to completion of key components of the trauma evaluation did not differ significantly between enrolled patients with family presence and those without family presence. Surveys were completed for 136 cases, and the majority of providers reported that family presence either had no effect on or improved medical decision-making (97%), institution of patient care (94%), communication among providers (92%), and communication with family members (98%).
PMID: 17766498

Family-centered prehospital care.

Emerg Med Serv. 2001 Jun;30(6):64-7, 83.
Loyacono TR.

Family-centered care is a mutually beneficial collaboration between patients, family members, and healthcare professionals to improve the overall health and safety of the community.

Because of their frequent presence at prehospital emergency scenes, family members often participate in prehospital care prior to the arrival of EMS. EMS professionals generally have little or no training in managing family members or in integrating their needs into the needs of their patients. Many EMS professionals believe interacting with family members is a matter of common sense, but our multicultural environment and advances in medical technology make the issue more complex. EMS professionals favor most family-centered care concepts, but are hesitant to open their patient compartments or their advisory boards to family members.
PMID: 10552201

Working with Families to Enhance Emergency Medical Services for Children - A Guidebook for EMSC Family Advocates.
EMSC National Resource Center. Washington, DC. 2001.

This guidebook is designed for individuals who share the desire to advocate for a better emergency health care system for children. It briefly describes the vision and goals of the Federal EMSC Program and the criteria and responsibilities of the family advocate. This booklet can be viewed at http://www.mchb.hrsa.gov/emsc.

Patient and family-centered collaborative care: an orthopaedic model.
Clin Orthop Relat Res. 2007 Oct;463:13-9.
DiGioia A 3rd, Greenhouse PK, Levison TJ.

Despite both longstanding and recent interest in patient-centered care, few published models or methods exist for defining and implementing patient-centered care in the office and hospital setting through a full cycle of care from the patient's perspective. This study describes patient- and family- centered collaborative care as a low-technology, systems-based solution to many current problems and suggest ways to provide safe, effective, timely, and efficient health care. Data was collected on 618 consecutive patients undergoing THA and TKA within a dedicated patient- and family- centered collaborative care program. It is a comprehensive systems-based approach that focuses on the full cycle of care while placing patients and their families as the top priority to provide high quality health care.
PMID: 17960670

And the Journey Continues... Achieving Cultural and Linguistic Competence in Systems Serving Children and Youth with Special Health Care Needs and their Families.
The National Center for Cultural Competence.

While the examples are related to State Title V programs for children and youth with special health care needs, this monograph is designed to offer insights and lessons learned by the NCCC during the past 13 years as they relate to the issues of cultural and linguistic competence in health and mental health systems. The document can be viewed at http://www.gucchdgeorgetown.net/NCCC/journey/.

Appendix A

Example Fact Sheet from Colorado EMSC

The EMSC Program: Taking Action, Saving Lives

The federal Emergency Medical Services for Children (EMSC) program supports projects in the states to expand and improve emergency medical services for children who need treatment for life threatening illnesses or injuries. The program has funded pediatric emergency care improvement initiatives in every state, the District of Columbia, and five U.S. territories. Some examples of cutting-edge work underway with support from the EMSC program are projects to: develop emergency care educational and training programs for school officials and staff; design national, evidence-based quality measures for assessing care to children who have suffered serious injuries; and ensure that all state disaster plans address pediatric needs.

Emergency Medical Care Needs of Children

- There are 31 million child and adolescent visits to the nation's emergency departments every year. Children under the age of three years account for most of these visits.

- Ninety percent of children requiring emergency care are seen in general hospitals versus freestanding children's hospitals. In a typical general hospital emergency department, one-quarter to one-third of the patients are children.

- Severe asthma and respiratory distress are the most common emergencies for pediatric patients, representing nearly one-third of all hospitalizations among children under the age of 15 years. Seizures, shock and airway obstruction are other common pediatric emergencies, followed by cardiac arrest and severe trauma.

Current Colorado EMSC Grant: "EMS Data System"

The availability of complete, accurate and timely information on the emergency medical services (EMS) care of the pediatric patient is critical for resource planning, evaluation of services, and identification of training needs. Colorado's lack of a statewide EMS data collection system for assessment and quality improvement has been identified, documented and targeted over the last two decades with little or no success.

The goal and objectives of this project focus on building capacity for EMS data collection, analysis and quality improvement at the local, regional and state levels. The design and funding resources takes into account both historical data collection aspects and the collaborative resource sharing approach. The current EMSC Partnership Grant is in its third year to develop an EMS Data System.

Previous EMSC Grant Accomplishments

Since its establishment in 1984, the EMSC effort has improved the availability of child-size equipment in ambulances and emergency departments. It has initiated hundreds of programs to prevent injuries, and has provided thousands of hours of training to EMTs, paramedics and other emergency medical care providers. EMSC efforts have led to legislation mandating programs in several states, and to educational materials covering every aspect of pediatric emergency care. Most importantly, EMSC efforts are saving kids' lives. Although EMSC has made great progress over the years, much remains to be done to ensure children receive optimal medical care.

The "First Care for Schools" course was developed with Colorado's second EMSC Partnership Grant in 1997-2000. The Colorado Emergency Medical Services for Children (EMSC) School Health Project with the support of the St. Mary's Hospital EMS Outreach Office, Grand Junction, Colorado developed the public school based course. This course addresses the

training needs identified in a statewide assessment of health care in Colorado public schools in 1998-1999 by the EMSC Partnership. Successful completion of this course enhances the emergency skills and knowledge of the most frequent health care providers in schools as identified in the assessment. The target audiences for this training are school staff members that are on the front lines of emergency and daily health care. Secretaries provide the majority (54%) of health care in Colorado public schools, followed by health aides (17%), principals (15%), and teachers (14%).

Currently, the course is offered across the state at over fifty school districts and some are in their fifth year. There is no fee for the course and it can be downloaded via our web page www.cdphe.state.co.us/em/emhom.htm.

The Pediatric Emergency Care Committee (PECC) has been a standing committee of the State Emergency Medical and Trauma Advisory Council (SEMTAC), since the beginning of the Colorado EMS program. The PECC is charged with addressing pediatric issues related to the emergency medical and trauma services system. SEMTAC is a governor appointed council to address the EMS and Trauma issues, programs and provide guidance and direction to the state EMS and Trauma Programs.

EMSC is primarily supported and is administered by the U.S. Department of Health and Human Services' Health Resources and Services Administration and the U.S. Department of Transportation's National Highway Traffic Safety Administration. Other EMSC sponsors include the Robert Wood Johnson Foundation, the National Fire Protection Association, and the Agency for Healthcare Research and Quality. General Motors and Smith-Kline Beecham have been corporate supporters.

For Further Information:
www.cdphe.state.co.us/em/emhom.html
Federal EMSC Program: http://mchb.hrsa.gov/emsc

Example Fact Sheet from Idaho EMSC

The EMSC Program: Taking Action, Saving Lives

The federal Emergency Medical Services for Children (EMSC) Program supports projects in the states to expand and improve emergency medical services for children who need treatment for life threatening illnesses or injuries. The program has funded pediatric emergency care improvement initiatives in every state, the District of Columbia, and five U.S. territories. The EMSC Program has developed several measurable goals for its grantees to ensure continued progress in critical areas of pediatric emergency care. Idaho is striving to improve its operational capacity to provide pediatric emergency care by, among other initiatives, increasing the number of: ambulances with essential pediatric equipment and supplies, emergency medical services agencies providing physician-directed care at the scene of an emergency, and hospitals with written agreements to transfer critically ill and injured children to facilities capable of handling their needs.

Emergency Medical Care Needs of Children in Idaho

- Children (age 0 to 17 years) make up 26% of Idaho's population (374,000).1
- In 2005, an average of 21 responses per day were made to children who had illnesses or injuries severe enough for 911 to be called for a total of 7,546 responses (10% of all 2005 PCR reported EMS calls in Idaho).
    - Illness accounted for an average of 8 responses a day for a total of 3,065
    - Injury accounted for an average of 11 responses a day for a total of 3,807 (includes 165 Alcohol/ Drug related calls)
        - Top Three Injury Responses:
            - Motor Vehicles = 4.5/day
            - Other Traumatic Events = 2.5/day
            - Falls = 2/day
    - Remaining 673 responses not categorized or coded as 'Other'
- In 2005, there were 241 deaths in Idaho for children under 18. Of these, 80 were caused by either intentional or unintentional injury.
- Every year, our nation's emergency departments receive about 40.9 million visits by children and adolescents (ages 0-24). These visits represent over one-third of all annual emergency department visits in the United States.2
- While most (90 percent) U.S. hospitals admit pediatric patients, less than half (40 percent) have separate inpatient pediatric wards.3
- Even though half (50 percent) of U.S. hospitals surveyed have most (85 percent) of the recommended pediatric medical supplies, very few (less than 6 percent) have all the supplies in the full range of sizes.3
- Sixty-two percent of the nation's emergency departments have board-certified pediatric physicians on call or available elsewhere within the hospital, but only 25 percent of emergency departments have written protocols outlining when to call in the specialist.3

Current Grant

Idaho's current EMSC Partnership Grant is funding the following goals and objectives:

1. Collect baseline data for each of the EMSC performance measures and submit data by October 2006 and annually thereafter
2. Establish an EMSC Advisory Committee with all required members (complete)
3. Improve the degree to which the state has established permanence of EMSC in the state's EMS system
4. Insure that 90% of BLS and ALS provider agencies within Idaho meet the essential AAP and ACEP joint pediatric equipment guidelines
5. Adopt requirements for pediatric emergency education for the recertification of paramedics

Previous EMSC Grant Accomplishments

In 2002, the project established a baseline assessment of EMSC in Idaho and identified opportunities for improvement. Taking an evidence-based approach to quality improvement, we conducted a descriptive analysis of three years of EMSC data specific to pediatric morbidity. The analysis was able to tell us that Idaho EMS personnel care for over 75,000 patients a year. Eleven percent, or over 8,000, of those patients are children between 0-17 years of age.

In 2004, the Idaho EMSC Program delivered Prehospital Pediatric Care (PPC) courses throughout the state, seeding each region with qualified instructors in pediatric education. Pre- and post-tests showed an increase in student knowledge in the basic life support class by an average of 25 percent.

In the fall of 2005, the Idaho EMSC Program helped sponsor a Medical Director conference with a focus in pediatric training. Evaluations from the conference were favorable.

Partnerships

Idaho EMSC partnered with Idaho State University Institute of Rural Health and created a child trauma card entitled "Dealing with your Child's Emergency" targeted to parents and providers. The card focuses on mitigating stress in children through the process of care to discharge.

We have also teamed up with the Paramedic Programs at both Idaho State University and the College of Southern Idaho to deliver quality pediatric education programs. Having purchased each site an infant simulated manikin (SimBaby), we will begin assessing skills education and knowledge retention among EMS providers who have received pediatric training using the manikin starting in the summer of 2007.

The EMSC subcommittee is now a standing subcommittee of the Idaho EMS Advisory Council (EMSAC). Committee members include representation from Idaho Office of Highway Safety, American Academy of Pediatrics, American College of Emergency Physicians, School Nurse Organization of Idaho, Idaho Hospital Association, emergency nurses and EMTs.

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Appendix B

Frequently Used Terms and Acronyms in EMSC

A

Abstract	A summary of a journal article, presentation submission, or grant application.
ACLS	Advanced Cardiac Life Support, includes electricity (defibrillator) and drugs for life threatening conditions.
ACEP Guidelines	American College of Emergency Physicians Guidelines.
Acute care	Providing or concerned with short-term medical care especially for serious acute disease or trauma (e.g., ED, trauma center) Part of the Continuum of Care. EMSC History
ADA:	Americans with Disabilities Act of 1990
Advance directives	Pertain to treatment preferences and the designation of a surrogate decision-maker in the event that a person should become unable to make medical decisions on their own behalf (e.g., living will, power of attorney, health care proxy).
AED	Automated external defibrillators deliver an electrical shock to the heart to restore its normal rhythm, enabling oxygenated blood to circulate to vital organs. Once only used by medical personnel, the public now has access to them.
Ambulatory care	Medical care (including diagnosis, observation, treatment and rehabilitation) provided on an outpatient basis.
ALS	Advance Life Support providers administer certain life-saving medications, perform advanced monitoring of heart rhythms, and are trained to perform advanced procedures to open and manage a patient's airway. They include EMT-Paramedics and EMT-Intermediate (EMT-I) and Cardiac Rescue.
APLS	Advanced Pediatric Life Support, an educational program for physicians.
Appropriations act	Act of a legislative body that makes funds available for expenditure with specific limitations as to amount, purpose, and duration.
Authorization act	Legislation that empowers an agency to implement a particular program and also establishes an upper limit on the amount of funds that can be appropriated for that program.

B

BELSS	Basic Emergency Life Saving Skills, a project to identify developmentally appropriate levels at which students in grades K-12 could receive education and training in first aid, rescue breathing, and CPR.
Block grant	A consolidated grant of Ffunds, formerly allocated for specific programs, that a state or local government may use at its discretion for such programs as education or urban development.
BLS	Basic Life Support; includes CPR and removal of foreign body airway obstruction
Broselow tapes	Short for Broselow-Luten emergency tape, a color-coded system used to simplify the use of medications and equipment in pediatric emergency settings
Bystander care	Emergency roadway assistance by a bystander that includes recognizing an emergency, stopping to help, calling for help, starting breathing, and stopping bleeding.

C

Call for Abstracts:	An announcement for potential presenters to submit summary statements of their presentation to a review panel for consideration.
Categorization:	An effort to identify the readiness and capability of a health care facility and its staff to provide optimal emergency care. EMSC History
CHUMS:	Child Health Updated Medical Summary
Color-Coding:	A strategy designed to eliminate errors in the treatment of children related to wrong dosages of medicines, incorrect amounts of fluids, and wrong sizes of equipment.
Continuum of Care:	A "seamless" system of care that includes prevention, prehospital care, ED care, inpatient and critical care, and follow-up care including rehabilitation.
Contract Officer:	A person with the authority to enter into, administer, and/or terminate contracts and make related determinations and findings.
Cooperative Agreement:	A financial assistance mechanism to be used in lieu of a grant when the awarding office anticipates substantial Federal programmatic involvement with the recipient during performance.
CODES:	Crash Outcome Data Evaluation System
CPR:	Cardiopulmonary resuscitation, which involves breathing for the victim and applying external chest compression to make the heart pump.
Critical Paths:	Documentation of essential steps in the diagnosis and treatment of a condition or the performance of a condition, and development of a standard pattern of care to be followed for each patient.
CSHCN:	Children with Special Health Care Needs
Cultural Competence:	Integration of culturally-sensitive approaches to products and services. Sensitivity addresses language barriers, geographic differences, and other culturally-based distinctions.

D

Demonstration Projects:	A Federal term for grant-funded projects designed to demonstrate on a particular issue, for a stated period of grant funding.
Discretionary Funds:	Any funds whose distribution is not automatic. Decisions on the distribution of discretionary funds are usually made by an agency on the basis of that agency's choice or judgment and in accordance with criteria set out in law or regulations.
DNR:	Do Not Resuscitate, which is requested or ordered for terminally ill patients.

E

E9-1-1:	Enhanced 9-1-1 universal emergency communications number that automatically identifies the telephone number and location of the caller.
ECHO:	Everyone Can Help Others
ECIC:	Emergency Communications & Information Center at CNMC.
ED:	Emergency department
EDAP:	Emergency Departments Approved for Pediatrics
EMS:	Emergency Medical Services
EMT:	Emergency Medical Technician (Basic, Intermediate, or Paramedic accredited).
EMTALA:	Emergency Medical Treatment and Labor Act, the Federal "anti-dumping law" that ensures that emergency care is provided to anyone who needs it, regardless of their ability to pay or insurance coverage.
EPROS:	EMSC Product/Resource/Order System, internal database of EMSC and non-EMSC products or resources that are determined to be useful or effective by NRC staff.

F

Facility Recognition	Classification of a hospital emergency department where staff are specially trained to care for children, using appropriate pediatric equipment and following guidelines for age-appropriate medications
Family-Centered Care:	An approach to health care that offers a new way of thinking about the relationships between families and health care providers (e.g., emotional, social, developmental support).
FARS:	Fatality Analysis Reporting System, designed to assist the traffic safety community in identifying traffic safety problems and evaluating both motor vehicle safety standards and highway safety initiatives.
Federal Register:	Government document announcing the availability and deadlines for applying for Federal grant programs.
First Responder:	The initial level of care within an EMS system as defined by the EMS Education and Practice Blueprint, as opposed to a bystander.
402 Funds:	DOT funds to support state highway safety programs designed to reduce traffic crashes and resulting deaths, injuries, and property damage.
FY:	Fiscal Year, a business year for an organization. For the Federal government and the NRC, it is October 1 through September 30. For CNMC, it is July 1 through June 30.

G

Glasgow Coma Scale:	This scale is used to quickly determine the status and degree of injury of a trauma victim to the head.
GMO:	Grants Management Officer, the official responsible for the business management aspects of particular grants or cooperative agreements.
GPRA:	Government Performance and Results Act
GME:	Graduate Medical Education, the period of medical training that follows graduation from medical school; commonly referred to as internship, residency, and fellowship training.
Grant Guidance:	Supporting documentation for Federal grant applications.

H

Healthy People 2010:	The prevention agenda for the nation. It is a statement of national opportunities—a tool that identifies the most significant preventable threats to health and focuses public and private sector efforts to address those threats.

I

I/O:	Intraosseous Infusion, a medical procedure that can be used to bypass the veins and inject critical fluids directly into the bone marrow.
ICD-9:	International Classification of Diseases, Ninth Edition, is the classification of diseases by diagnosis with four-digit numbers or alphanumeric descriptions. Used for billing purposes by hospitals and physicians.
ICU:	Intensive Care Unit, having special medical facilities, services, and monitoring devices to meet the needs of gravely ill patients.
Institutionalization:	The formal establishment of EMSC through the legislative or regulatory process, or by securing a private long-term funding commitment.

Interfacility transfer agreements:	Written contracts between a referring facility (e.g., community hospital) and a specialized pediatric center or facility with a higher level of care and the appropriate resources to provide needed care required by the child. The agreements must formalize arrangements for consulta tion and transport of a pediatric patient to the higher-level care facility.
Interfacility transfer guidelines:	Hospital-to-hospital, including out of state/Territory, guidelines that outline procedural and administrative policies for transferring critically ill pediatric patients to facilities that provide specialized pediatric care.
Intubation:	Insertion of an endotracheal tube to help an unconscious patient breathe.
IRECC:	Intermountain Regional EMSC Coordinating Council, a consortium of Rocky Mountain states that share common rural and frontier issues concerning EMSC.
ISS:	Injury Severity Score
M	
M&M:	Morbidity/Mortality, is a conference held by many departments on cases that either ended in death (where there was an interesting diagnosis)--mortality, or someone with a good diagnosis -- morbidity.
Managed Care:	Any form of health care plan that contracts selectively with providers, employers, or insurers to channel employees or patients to a specified set of cost-effective providers (a provider net- work). Providers implement procedures to ensure medically necessary and appropriate use of health care services.
MCH:	Maternal and Child Health
Medicaid:	A program of medical aid designed for those unable to afford regular medical service and financed jointly by the state and Federal governments.
Medical Control:	Physician oversight of care provided by prehospital personnel. On-line medical control con- cerns real-time direction of prehospital providers by designated medical personnel. Off-line medical control relates to policies, training, and quality assurance.
Medical Home:	A concept of medical care that ideally is accessible, continuous, comprehensive, family-cen- tered, coordinated, and compassionate.
Medicare:	A government program of medical care especially for the elderly.
Morbidity:	A measure of disease incidence or prevalence in a given population, location, or other grouping of interest.
Mortality:	A measure of deaths in a given population, location, or other grouping of interest.
MVA	Motor Vehicle Accident
N	
Needs Assessment:	Systematic appraisal of the type, depth, and scope of a problem.
NICU:	Neo-natal Intensive Care Unit
O	
Off-line Medical Direction:	Treatment guidelines and protocols used by EMS providers to ensure the provision of appropriate pediatric patient care, available in written or electronic (e.g., laptop computer) form in the patient care unit or with a provider, at the scene of an emergency.
On-line Medical Direction:	An individual is available 24/7 on the telephone, radio, or email to EMS providers who need on-line medical direction when transporting a pediatric patient to a hospital. The health profes- sional (e.g., nurse, physician, physician assistant, EMT) providing medical direction is deemed to have pediatric expertise by the hospital in which they work and must have a higher level of pediatric training/expertise than the EMS provider to whom he/she is providing medical direction.

Outcome Evaluation:	Used to obtain descriptive data on a project and to document short-term results.
Outcome Standards:	Long-term objectives that define optimal, measurable future levels of health status, maximum acceptable levels of disease, injury, or dysfunction, or prevalence of risk factors.
Outcome:	The consequence of a medical intervention on a patient.
Outcomes Research:	Medical or health services research that attempts to identify the clinical outcomes (including mortality, morbidity, and functional status) of the delivery of health care.
P	
PACE:	Planning to Avoid Childhood Emergencies
PALS:	Pediatric Advanced Life Support, an educational program for health care providers (e.g., physicians, nurses, EMTs)
Patient Care Units	any vehicle owned by an entity responsible for 911 services (eg; hospital, fire department, law enforcement, community, etc.) that is licensed/regulated by the state/territory/county/local jurisdiction and is staffed by state/territory/county/local jurisdiction certified/licensed prehospital personnel whose primary responsibility is delivering emergency medical care to any and all patients in the out-of-hospital setting. This definition excludes any individual's personal vehicle(s).
PCC:	Poison Control Center
PEP:	Pediatric Education for Prehospital Providers course.
Performance Measure:	A specific measure of how well a health plan does in providing health services to its enrolled population. Can be used as a measure of quality.
PFC:	EMS Partnership for Children Consortium
PI:	Principle Investigator, the individual designated by the recipient to direct the project or program being supported by the grant, and is responsible to recipient organization officials for the proper conduct of the project or program.
PIC:	MCH Partnership for Information and Communication Inter-organizational Work Group explores emerging policy issues affecting the health of mothers and children. PIC members include governmental, professional, and private sector organizations that have received MCHB grants.
PICU:	Pediatric Intensive Care Unit
PI&E:	Public information and education
Practice Guideline:	An explicit statement of what is known and believed about the benefits, risks, and costs of particular courses of medical action, and intended to assist decisions by practitioners, patients, and others about appropriate health care for specific clinical conditions.
Prehospital:	Time or care that occurs before or during transportation to a hospital. Part of the Continuum of Care. EMSC History
Prevention:	Actions taken to reduce susceptibility or exposure to health problems (primary prevention), detect and treat disease in early stages (secondary prevention), or alleviate the effects of disease and injury (tertiary prevention). Part of the Continuum of Care. EMSC History
Primary Care:	A basic level of health care provided by the physician from whom an individual has an ongoing relationship and who knows the patient's medical history (e.g., preventive services, treatment of minor illnesses/injuries, identification of problems that require referral to specialists). Traditionally, primary care physicians are family physicians, internists, gynecologists and pediatricians.
Process Evaluation:	Examination of the procedures and tasks involved in implementing a program.
Program/Project Officer:	An official who is responsible for the technical, scientific, or programmatic aspects of a grant, and works closely with the Grants Management Officer in the overall administration of grants.
Project Coordinator:	The individual responsible for executing activities supported by the grant, and directed by the PI or Project Director.

Project Director:	The individual designated by the recipient to direct the project or program being supported by the grant, and is responsible to recipient organization officials for the proper conduct of the project or program.
Protocols:	Standardized guidelines for treatment procedures. EMSC History
Public Health:	Activities that society does collectively to assure the conditions in which people can be healthy. This includes organized community efforts to prevent, identify, preempt, and counter threats to the public's health.
Q	
Quality Assurance:	A formal, systematic process to improve quality of care that includes monitoring quality, identifying inadequacies in delivery of care, and correcting those inadequacies.
QUART:	NRC database that once information is entered into, can breakdowns actions by scope of work and generates reports for quarterly reporting requirements to MCHB.
R	
Regionalization:	A formal effort by outside agencies to specify particular institutions that can offer complex, sophisticated services in a specific geographic area.
Registry:	A repository for information that is used for data collection.
Regulation:	A governmental order with the force of law.
Rehabilitation:	The physical restoration of a sick or disabled person by therapeutic measures and reeducation to participation in the activities of a normal life within the limitations of the person's physical disability. Part of the Continuum of Care. EMSC History
RFP:	Request for Proposals, a funding announcement used by the Federal government to solicit proposals from applicants.
S	
SCHIP:	State's Child Health Insurance Program
Septic Shock	Septic shock is a serious medical condition caused by decreased tissue perfusion and oxygen delivery as a result of infection and sepsis. It can cause multiple organ failure and death. Its most common victims are children, immunocompromised individuals, and the elderly, as their immune systems cannot cope with the infection as well as healthy adults are able. The mortality rate from septic shock is approximately 50%.
SKIP:	Special Kids Information Program
SPRANS:	Special Projects of Regional and National Significance (MCH Block grant funded)
Strategic Plan:	A comprehensive, incorporating goals, objectives, activities, and evaluation.
Surveillance:	Observation of a particular issue to collect data.
T	
TAD:	Technical Assistance Database, the EMSC database that includes contact information, organization information, and technical assistance action.
TBI:	Traumatic Brain Injury
Technical Assistance:	Provision of expert advice or guidance.
Telemedicine:	The investigation, monitoring, and management of patients and the education of patients and staff using systems which allow ready access to expert advice and patient information, no matter where the patient or the relevant information is located.

Tertiary Care:	Highly specialized health care usually over an extended period of time that involves advanced and complex procedures and treatments performed by medical specialists in state-of-the-art facilities.
Three-Point Restraint:	Three adjoining points where automotive lap and shoulder safety belts meet. Safety standard established by DOT.
Title V:	Title V of the Social Security Act, which authorizes the MCH Block grant and other MCH programs.
Tracheostomy:	The surgical formation of an opening into the trachea through the neck especially to allow the passage of air.
Transport:	The means by which ill or injured are transported to care (may be ground, air, or water). EMSC History
Trauma:	An injury caused by a physical force. Most often the consequences of motor vehicle crashes, falls, drowning, gun shots, fires and burns, stabbing, or blunt assault.
TRIPP:	An encyclopedic resource guide that helps instructors teach ambulance personnel basic life-saving procedures for children.
Trust Funds:	Accounts established by law to hold receipts collected by the Federal government and ear-marked for specific purposes and programs. These receipts are not available for the general purposes of the Federal government.
W	
White Papers:	Topic-specific papers developed by experts that generally provide recommendations for addressing a particular issue.
Work Plan:	A plan of activities to be carried out to meet the scope of work approved in a grant or contract.

Appendix C

How A Bill Becomes A Law

Step 1 – Legislation is introduced in the House of Representatives (House) and/or Senate and assigned a number.

- Any Member of Congress may introduce legislation, which is commonly referred to as a "bill."
- Each bill is assigned a number; this numbering system is sequential but separate between the House and Senate.
- Each bill number is preceded by "HR" in the House and "S" in the Senate. HR stands for House Resolution.

Step 2 – Legislation is referred to the House or Senate committee of jurisdiction.

- For example, an education bill would be referred to the committee handling education issues.
- The bill can be further referred to a subcommittee; for example, a bill on elementary education might be referred to the subcommittee on elementary education.

Key Committees Important to EMSC Program Reauthorization
House – Committee on Energy and Commerce, Subcommittee on Health
Senate – Committee on Health, Education, Labor and Pensions (HELP)

Step 3 – The House or Senate committee or subcommittee of jurisdiction may hold a hearing on the bill.

- Such a hearing is not for public, oral comment, although most times the public can attend, but for oral comment by invited witnesses for purposes of information gathering.

Step 4 – The House or Senate committee of jurisdiction may mark-up, or edit, the bill. The committee then votes on the bill and reports it, or passes it on, for consideration by the entire House or Senate.

- If the committee does not mark-up and report out the bill before the end of the two-year Congressional session, the bill "dies." To be receive consideration again, the bill must be reintroduced in the next Congressional session, where the process starts over again.

Step 5 – The House or Senate may debate, amend, and vote on the bill. If the bill passed on the floor of the House or Senate, it is referred to the other chamber for consideration. Unless the other chamber already has a similar measure under consideration, the bill is referred to committee.

- Again, if both the House and Senate do not debate and vote on the bill before the end of the two year session, it dies.
- If the bill is voted down by either chamber of Congress, the bill may die. Sometimes a bill is sent back to committee for further amending, after which it may be considered again on the floor.

Step 6 – If both the House and Senate pass the same bill, it is sent to the President for his signature (see Step 9).

Step 7 – If the House and Senate pass different versions of the bill, each chamber appoints members to a conference committee. The conference committee works out the differences between the two versions of the bill and drafts a "conference agreement" or compromise version of the bill.

Step 8 – The House and Senate vote on the conference agreement. If it passes both chambers, it is sent to the President for his signature.

Step 9 – The President either signs the bill into law or vetoes the bill.

Step 10 – If the President vetoes the bill, two-thirds of the House and Senate can vote to override the President's veto. If the veto is overridden, the bill becomes law.

Appendix D

The Budget and Appropriations Process

Step 1 – *The President's Budget.* Each year, on our before the first Monday in February, the President releases his budget request for the upcoming fiscal year. For example, the Fiscal Year 2009 (October 1, 2008 through September 30, 2009) budget is released in February 2008. The President's budget is a non-binding proposal containing detailed funding recommendations for Federal agencies and programs for the year. Again, the President's budget merely sets forth the executive branch's budget priorities for the next fiscal year. It is not a bill and it isn't a law.

Step 2 – *The Congressional Budget Resolution.* Each year Congress drafts a budget resolution, which outlines its financial priorities for the coming fiscal year. Instead of containing detailed funding recommendations for Federal agencies and programs, the resolution sets general spending limits on Federal activities. For example, the resolution sets a spending limit for the entire Department of Health and Human Services; it does not recommend specific funding levels for individual programs within the department, such as the EMSC Program.

The congressional budget resolution often varies from the President's budget request. Although Congress votes on the budget resolution, typically in April, it is not signed into law by the President.

Step 3 – *The Appropriations Process.* Appropriations bills provide funding for Federal agencies and programs. Each fiscal year, Congress considers approximately 12 appropriations bills; a single appropriations bill may provide funding for multiple agencies and programs (e.g., the Departments of Labor-Health and Human Services-Education (L-HHS) appropriations bill funds programs within those three departments). The congressional budget resolution defines the total amount Congress can appropriate to all Federal agencies and programs for a given fiscal year.

In considering the L-HHS appropriations bill, which includes funding for the EMSC Program, Congress follows a slightly varied legislative process.

Step A – The L-HHS Subcommittee of the House Appropriations Committee introduces the appropriations bill. The Subcommittee marks-up, or edits, the bill. The Subcommittee then votes on the bill and reports it, or passes it on, to the full House Appropriations Committee. This process is supposed to begin in May.

Step B – The House Appropriations Committee marks-up, or edits, the bill. The Committee then votes on the bill and reports it to the House of Representatives.

Step C – The House debates, amends, and votes on the bill. If the bill is passed, it is referred to the Senate, specifically to the L-HHS Subcommittee of the Senate Appropriations Committee. This is supposed to be completed by June.

Step D – The Senate Subcommittee marks-up, or edits, the bill. The Subcommittee then votes on the bill and reports it to the full Senate Appropriations Committee.

Step E – The Senate Appropriations Committee marks-up, or edits, the bill. The Committee then votes on the bill and reports it to the Senate.

Step F – The Senate debates, amends and votes on the bill.

Step G – If both the House and Senate pass the same version of the bill, it is sent to the President for his signature (see Step J).

Step H – If the House and Senate pass different versions of the bill, each chamber appoints members to a conference committee. The conference committee works out the differences between the two versions of the bill and produces a conference agreement (a final, compromise version of the bill).

Step I – The House and Senate vote on the conference agreement. If it passes, it is sent to the President for his signature.

Step J – The President either signs the bill into law, ideally in time for the beginning of the fiscal year on October 1, or he vetoes the bill.

Step K – If the President vetoes the bill, two-thirds of the House and Senate can vote to override the President's veto. If the veto is overridden, the bill becomes law. If the veto is not overridden, Congress must revise the bill and send the revised version to the President.

Appendix E

On-line Resources of Interest to Family Representatives

A Family Preparedness Guide
http://www.michigan.gov/homeland/0,1607,7-173--25233--,00.html

A site dealing with Homeland Security issues. Information on ricin, acute radiation, and chemical agents. Basically a site exploring aspects of terrorism and public health.

AAP Offers Advice on Communicating with Children about Disasters
http://www.aap.org/advocacy/releases/disastercomm.htm

In the aftermath of Hurricane Katrina, the AAP developed a list of resources designed to help parents and other care providers prepare children in advance of a disaster and then deal with the emotional well-being after a disaster.

Are You Ready? An In-depth Guide to Citizen Preparedness (IS-22).
http://www.ready.gov/america/index.html

The Federal Emergency Management Agency's (FEMA) most comprehensive source on individual, family, and community preparedness detailing the steps needed to prepare a disaster plan and assemble an emergency kit. The side includes an illustrated section for kids covering the same information. Includes contact information to all FEMA offices from the county level upwards.

Child and Adolescent Mental Health
http://www.mentalhealth.samhsa.gov/child/childhealth.asp

This site links users to ten other organizations dealing with youth mental health, and includes such resources as A Guide to Keeping Youth Healthy and Drug Free and Youth Violence Prevention.

Child and Adolescent Psychological and Educational Resources
http://www.caper.com.au/

This site has been active since 2001 and, over time, has built up a large information base, accessed internationally by students, teachers, researchers, and other professionals interested in research and practical resources relating to children, adolescents and families. Particular focus is given to issues relating to peer relationships, including bullying, as well as stress and wellbeing.

Child Safety – Children, Youth, and Women's Health Services
http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=305&id=1725

This Australian website provides quick information on a comprehensive list of childhood ailments and injuries. Some of the categories covered include: health and nutrition, family and relationships, healthy life style, infections and immunizations, safety and first aid, and disabilities.

Emergency Mental Health and Traumatic Stress
http://www.mentalhealth.samhsa.gov/cmhs/EmergencyServices/after.asp

The site, titled Tips for Talking About Disasters, links to a number of one-page documents on the following topics: tips for teachers, for children and adolescents, for adults, for families, and for emergency and disaster response workers.

Emergency Preparedness for Children with Special Health Care Needs
http://www.aap.org/advocacy/emergprep.htm

To facilitate prompt and appropriate emergency care for children with special health care needs, the AAP and ACEP have developed an Emergency Information Form that can be used as a tool to transfer critical information about these children. It is hoped that the form will gain acceptance and be utilized by primary caregivers and specialists so that emergency physicians may have access to vital information when emergencies occur. The form and policy guidelines on developing emergency care plans can be found on this site.

Family Disaster Planning – American Red Cross
http://www.redcross.org/services/disaster/0,1082,0_601_,00.html

A page devoted to responding to natural disaster. Topics are grouped into four headings: find out what could happen to you, create a disaster plan, a checklist of preparations, and sticking to your plan.

Family Readiness Kit – Preparing to Handle Disasters
http://www.aap.org/family/frk/frkit.htm

This kit is for parents to use at home to help prepare for most kinds of disasters. It features a series of pdf documents dealing with such topics as knowing how to turn of the utilities and preparing a checklist of emergency supplies.

Family Violence and Bullying Prevention
http://child.alberta.ca/home/593.cfm

This Canadian site examines many different aspects of domestic violence and offers numerous links and resources to organizations or sites dealing with the issue.

Family Health Services Directory
http://www.health.wa.gov.au/services/category.cfm?Topic_ID=6

In Australia, there is a wide range of health support available for children and families including child health and development services, school health services, community health services, and women's health services. This site connects to the health support centers throughout the nation. Also included is a health topics medical encyclopedia, listing various topics and providing a definition and overview of each topic.

Healthfinder
http://www.healthfinder.gov/

Healthfinder, produced by the Department of Health and Human Services, is a well-known source of authoritative health information on the web. It features a information rich health library, with topics arranged alphabetically. Readers will also find a drug interaction checker, links to the latest health news, and links to health-related organizations.

In the Aftermath of Crisis: Parents' Guide to Talking with Children about Death
http://www.nccev.org/docs/children_death.pdf

This link takes the reader to the text of a talk given by Dr. David Schoenfeld and presents guidelines in explaining death to younger children.

Just for Kidz – Internet Safety
http://www.ftc.gov/bcp/conline/edcams/kidzprivacy/kidz.htm

This site is devoted to protecting children from online predators and thieves. It alerts children to the problem and tells them what to look for.

National Center for Injury Prevention and Control Fact Sheets
http://www.cdc.gov/ncipc/cmprfact.htm

Published by the Centers for Disease Control and Prevention, this site provides statistics and information on general and acute care injuries, unintentional injuries, and injuries as a result of violence. Sample topics include injuries by poisoning, water accidents, traffic accidents, but also child abuse, school shootings and youth violence. The site has links to a number of position papers with such titles as Best Practices of Youth Violence Prevention and National Strategies for Advancing Child Pedestrian Safety.

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EMSC
Emergency Medical
Services for Children
NATIONAL RESOURCE CENTER


Children's
National Medical Center