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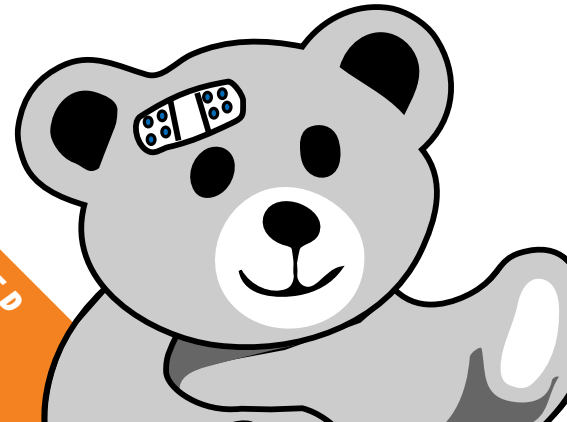
WORKING WITH FAMILIES

*To Enhance
Emergency Medical
Services for Children*



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Prepared by the EMSC National Resource Center, Washington, D.C.



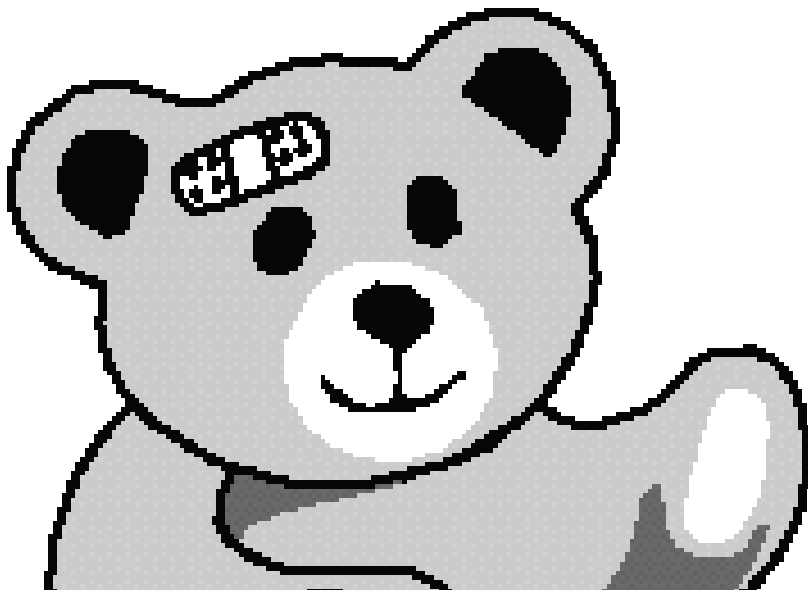
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TABLE OF CONTENTS

Introduction	4
What Is Family-centered Care?	4
Fundamental Concepts of Family-centered Care	4
Why Collaborate with Families?	5
Collaboration Benefits Providers	5
Collaboration Benefits Children and Their Families	5
Beginning A Process of Change: A Three-step Guide to Initiating Family Involvement	6
Step One: Identifying Family Advisors	6
Step Two: Initiating the Collaboration	6
Step Three: Keeping Families Involved	7
Facilitating Change Through Self-assessment Inventories	7
Appendices:	9
Appendix A: Building Family-centered EMS at the State Level: A Self-assessment Inventory	9
Appendix B: Developing Family-centered EMS at the Local Level: A Self-assessment Inventory	14
Appendix C: Family-centered Care In the Emergency Department: A Self-assessment Inventory	22
Appendix D: Community-based Advocacy Organizations	35
Appendix E: EMSC Family-centered Care Handout #1	37
Appendix F: EMSC Family-centered Care Handout #2	38
Appendix G: Bibliography	39

Working with Families to Enhance Emergency Medical Services for Children

Introduction

Developed by emergency care professionals and families who have experienced emergency care first hand, this guide is intended to help state and local emergency medical services (EMS) agencies, Emergency Medical Services for Children (EMSC) grantees, hospitals, and family advocates explore the concept of family-centered care and apply it to pediatric emergency medical services. Use it as a framework for facilitating discussion and collaboration. Practical information and tools for conducting internal family-centered assessments are also included.

What Is Family-centered Care?

The term "family-centered care" may be unfamiliar to many emergency care providers. Even those who are familiar with the concept may be unaware of its applicability to emergency care settings. Family-centered care is an approach to care characterized by mutually beneficial collaboration between patient, family, and health professional. 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.

Health care providers who adopt a family-centered approach know that, over time, families have the greatest influence on their child's health. They know that family members are profoundly involved in the physical and psychological well being of one another. A family-centered approach to emergency care nurtures strong bonds between children and their families and uses those relationships to assist in providing quality care and promoting children's overall health and safety. This approach also recognizes the expertise and range of experiences families bring to the health care system. For example, as consumers of emergency services, families can:

- assist in and/or improve direct patient care;
- design and evaluate programs and systems;
- provide input on organizational governance;
- support public policy and fundraising activities; and
- raise public awareness about specific issues.

Recent changes in how health care systems are being financed — the advent of managed care, for example — have made many health care administrators and direct care providers realize the importance of listening to consumers. Increasingly, families are being viewed not only as partners but as essential allies in the new health care environment.

Fundamental Concepts of Family-centered Care

- **Respect** – for each family's basic human dignity, expertise, values and culture, and the variety of ways in which they cope – should serve as the foundation for communication and relationships with families.
- **Strengths** can be found in every family, even in crisis situations. A skilled provider can use these strengths to help the child and family. For instance, a paramedic who asks a parent to hold a child's oxygen mask recognizes and reinforces the parent's role as a caregiver.
- **Choice** is also essential. Family-centered care recognizes that families are very diverse and will make different choices for their children. For example, some parents prefer to remain with their children during resuscitation, an intervenous start, or a spinal tap. Others do not. Family-centered practitioners convey respect for the choices that families make.
- **Information** helps families make choices and provide better care. It is important that families have access to complete and easy-to-understand information about their child's care. Discharge instructions, brochures, and other materials must be available in a variety of formats for both out-of-hospital and in-hospital settings. This may include information translated into Spanish or other languages for those who do not speak English, video or audiotapes for families who cannot read, and closed-captioned videotapes for those who are deaf or hearing impaired.
- **Support** is needed by everyone in a health crisis, but varies from family to family. Many trauma teams assign a dedicated liaison to the family, helping family members identify and secure the level of support they need and want.
- **Collaboration** is the heart of family-centered care. In the care of a child, families and health care personnel collaborate, as partners, to determine what is best for the child and family. For local EMS providers and hospitals, family members may advise the staff on policy questions which impact other families. For example, they may assist with the design of family satisfaction surveys; develop and teach family-centered orientation classes; or provide a family's perspective in the development of policies and procedures. At a systems level, families may serve on a variety of committees and advisory councils; educate the media and political leadership; or provide their special expertise and perspective in helping to make the entire delivery system more responsive to the needs and priorities of families.

Why Collaborate with Families?

Collaboration Benefits Providers

Many examples exist where a family-centered approach to care has helped EMS personnel, hospital staff, and families discover the benefits of working together. The following are some real life examples:

- Families are an invaluable source of information about their children's needs. In Massachusetts a mother of a child with special health needs created an emergency services care plan and shared it with local paramedics. As a result, local paramedics are better prepared to handle the unique needs of this child should an emergency occur.

Another family in rural Michigan, whose child depends on life support, collaborated with local paramedics and the ED staff to prepare them to care for their child in an emergency situation.

- Families advocate for improved pediatric emergency care at the local, state, and national levels. At the suggestion of a pediatrician in New Jersey, a parent member of the Junior League's Public Affairs Committee helped create a statewide coalition of families, emergency care providers, and others to secure passage of EMSC legislation.

- Families bring an important perspective to systems design. In Michigan, parents are involved in all phases of the development of the Medicaid managed care system. For example, parents who have experienced a medical emergency involving their child are invited to review and comment on the EMS sections of the Medicaid managed care "Request for Proposals."

- Families help improve communication and services in EDs. Admitting procedures and staffing patterns were changed and family satisfaction ratings improved for the ED at Children's Health Care-St. Paul as a result of discussions between ED staff and the hospital's Parent Advisory Council.

- Young people and siblings are also an invaluable source of ideas for outreach, education, and support. A Maryland ninth grader, protected from injury in a crash because he was wearing a bicycle helmet, worked with the National Organizations for Youth Safety to educate other youth of the risks of injury.

In the ED at Children's Hospital of Wisconsin in Milwaukee, youth serve as peer counselors for other youth who have been violently injured. Trained in strategies to reduce recidivism, they help build trusting relationships and connect the injured youth and their families to mental health agencies and violence services in the community.

- Family members bring important skills and perspectives to training programs for administrators and direct care providers. Parent to Parent of Vermont helped the state's health department plan the New England Regional EMSC Conference. This family-led organization is also developing education programs and standards of customer satisfaction for emergency care.

- Families help to raise public awareness. A family from Roosevelt, UT, agreed to share their experiences with emergency care in a video developed for national distribution. Others have shared their stories with the media.

- Families offer perspectives that enhance design planning and help hospitals avoid costly mistakes in facility design. At the Medical College of Georgia Hospital and Clinics, parents serve on the design planning team for new pediatric emergency facilities along with the director of pediatric emergency medicine, other staff, architects, and interior designers.

- Families bring connections to community resources, funders, and other organizations that can assist with statewide planning. In Florida, families and family organizations are working with EMS and other state agencies to establish protocols for managing emergencies during a disaster.

- Families help to ensure that programs and services are culturally effective. In Oklahoma, Native American families helped to develop a bystander care program for families living on reservations.

Collaboration Benefits Children and Their Families

Below are a few examples of how collaboration benefits children and families, those that use and depend on quality health care services.

- Involving parents/caregivers in the care provided to their children helps families cope. A family member said, "We stayed in the room during the attempts to resuscitate our son. There was no second-guessing. We knew how hard the team was working to save him."

- Allowing families to be present during medical procedures serves as a source of comfort to children. In Maryland, a father whose toddler nearly drowned said, "I pulled him out of the pool and my mother did cardiopulmonary resuscitation (CPR). When we got to the hospital, they said I couldn't come into the room. I couldn't understand why. We had already been with him during the most difficult part. I could hear him screaming for me. He was frantic. I could have helped him, and the doctors, by calming my son so they could do their job better."

- Encouraging families to participate on task forces, committees, and advisory boards helps organizations to improve the quality of care they provide. To improve family satisfaction of care, the Hasbro Children's Hospital in Rhode Island created a Family Advisory Council. One of the Council's first activities was to appoint a volunteer family liaison to improve communication and the flow of information to families waiting in the ED.

Tip: To prevent the feeling of isolation, consider including more than one family member on a committee. Some agency and hospital committees have found it beneficial to have consumers comprise at least one third of the membership.

Selecting Family Advisors

Successful family advisors are able to:

- articulate ideas clearly;
- ask questions;
- listen well;
- speak comfortably about their own situations;
- see beyond their own personal experience;
- respect the perspectives of others; and
- work in partnership with others.

**Beginning A Process of Change:
A Three-step Guide to Initiating Family Involvement**

The following guidelines are designed to help providers collaborate with consumers who are interested in planning, developing implementing, and evaluating emergency care.

Step One: Identifying Family Advisors

To identify a core group of family advisors within your state, contact community-based advocacy organizations, such as the Parent-Teacher Association, Family Voices, Parent Training and Information Centers, and Parent to Parent (see Appendix D for a list of community-based organizations and how to contact each). The EMSC National Resource Center's Family Advocacy Network (FAN) is another resource (see Appendix E). This group of individuals shares the desire to improve emergency and health care for children. FAN links its members with national, state, and local organizations involved in EMSC-related activities.

Additional suggestions for identifying family advisors include:

- Asking EMTs, paramedics, ED staff, discharge coordinators, and primary care providers to suggest families who might be interested.
- Asking existing family advisors to recommend others who might be interested in participating.
- Posting notices on bulletin boards in clinics and hospital EDs.
- Including information about family advisory roles in your consumer satisfaction surveys.
- Contacting Title V agencies and other programs in state and local health departments.
- Contacting providers of perinatal services and leaders in early intervention programs.
- Submitting "canned" or preproduced articles for placement in materials distributed by child care centers and schools.
- Placing posters in social service agencies, shopping areas, libraries, gas stations, banks, recreation centers, and any other areas where large crowds gather.

- Contacting leaders of cultural clubs and religious organizations that sponsor outreach projects serving families in the community.
- Posting requests for family advisors in chat rooms or on other sites on the Internet.

Step Two: Initiating the Collaboration

Successful collaboration with families does not happen overnight; it begins with small steps to get families involved. Over time, families and professionals learn together how this approach can be mutually beneficial in improving emergency care for children.

One of the most successful ways to initiate a relationship with parents is to invite those who have experienced a pediatric emergency to share information about their experiences with key members of your staff. This might be a single meeting or a brief series of meetings held at the state level or at a local EMS facility or a hospital's ED or critical care unit.

To ensure a successful and highly productive meeting, recruit participants that represent a variety of cultural backgrounds and health care experience. Consider hiring an outside meeting facilitator to help ensure the meeting is well organized and everyone has the opportunity to present his or her perspectives and ideas.

The meeting facilitator should open with a welcoming statement that addresses the purpose and value of gathering family perspectives. Be sure to acknowledge that collaborating with consumers in policy and program development is new for many providers, health policy makers, and families. It is a process in which everyone learns together how to work in new ways.

Spend extra time on introductions so that everyone knows who is participating and in what role. Remember that the primary purpose of the meeting is to solicit feedback from families on their emergency care experiences: what went well and what might have gone better; what improvements they would make if they could; and what policies and practices might support their suggested changes. Ask family members to describe the care provided by individual members of the emergency medical team and what behaviors were most helpful and why.

Meeting facilitators should provide refreshments and breaks for networking. In addition, remember to reimburse families for expenses incurred (travel, meals, child care, etc) and offer a

stipend for their time. Within a week following the meeting send a letter to each participant thanking them for sharing their perceptions and expertise, and reiterate how their input will be utilized.

Step Three: Keeping Families Involved

The initial meeting will generate many ideas for improvement as well as collaboration. Health care providers who participated will be more open to appointing families to committees and task forces and creating consumer advisory councils. Likewise, family participants will see the value their participation has in the improvement of care within their community.

In addition to sharing their health care experiences with hospital staff, consider asking families to participate in the following activities:

- advocating for better health care policies by sharing personal experiences and suggestions with political, business, and insurance leaders;
- assessing family-centered practices of state and local EMS services and hospitals (see "Facilitating Change Through Self-assessment Inventories," this page, column two, for more information);
- serving as spokespersons at news conferences and other media events;
- sharing their experiences in public service announcements or by submitting articles to newsletters and newspapers;
- developing and conducting outreach programs to prevent injury to children or to improve community competence in First Aid and CPR;
- developing community disaster plans;
- developing Medicaid managed care systems or other health care reform initiatives;
- serving as liaisons to families in the ED by offering comfort, answering basic questions, solving problems, and diffusing stress;
- training paramedics, ED staff, and other health care providers in family-centered approaches to care;
- developing consumer satisfaction surveys, public education materials, and community resource manuals;
- translating existing or new materials into Spanish and other languages;
- serving on design planning teams for ED renovation and construction projects; and
- networking with other families who have had similar experiences.

One way to build positive and constructive collaborative relationships among consumers and EMS/ED providers is to find opportunities for them to learn and plan together. Local, statewide, and national meetings offer these valuable experiences. When coordinating family participation in a meeting or conference, keep the following in mind:

- Make sure that a family member is able to pay on-site expenses or is given a travel advance. Reimburse families or pay them up-front for expenses, including transportation, hotel, registration fees, and child care. A local business or health plan may be willing to sponsor consumer participation.
- Provide information in advance about the meeting and about responsibilities during and following the meeting.
- Ask family participants if they have any questions, concerns, or issues about attending the meeting.
- Provide an orientation to the organization's structure, goals, and terminology.
- Create opportunities for families to network with other family members and providers before, during, and after the meeting.
- When possible, match new advisors with those who have already participated in family/professional collaborative meetings for mentoring and mutual support.
- Meet with family advisors after the meeting to debrief, answer questions, and learn about their experiences.
- Encourage families to participate in parent leadership or other professional development activities.

Tip: Many have found that having a family-centered steering committee, consisting of both professionals and families, can guide the process of change, serve as a resource for work groups addressing specific issues, and assist in evaluation. The steering committee can identify strategic opportunities, develop a comprehensive action plan, address obstacles as they emerge, coordinate efforts, and monitor progress over time.

Before asking consumers to participate in any activity clarify the purposes of each task and the role family members and others will play. Consumers need to decide if this is an activity that holds their interest, if it is worth their time, and if they have the skills needed to participate in the activity.

Facilitating Change Through Self-Assessment Inventories

Many individuals, local organizations, hospitals, and state agencies have found that conducting internal reviews of current policies, programs, staff practices, and facilities is an excellent way to begin a process of change and to advance the implementation of family-centered care. To help start this inside evaluation process, three assessment tools are included in this document:

- Building Family-Centered EMS at the State Level: A Self-assessment Inventory, (see Appendix A).
- Developing Family-Centered EMS at the Local Level: A Self-assessment Inventory, (see Appendix B).

- Family-Centered Care in the Emergency Department: A Self-assessment Inventory, (see Appendix C).

The first step in using these self-assessment inventories is to appoint a broad-based committee, task force, or team to conduct the assessment. This group should include all stakeholders, including individuals across disciplines and departments and consumers of EMS/ED services.

Each self-assessment inventory is quite detailed. The group should decide if it wants to use the entire tool or focus on just one or two sections. Others who have used similar tools to further the implementation of family-centered care in child health services have found that, through this collaborative process, they:

- Learn about family-centered care and its practical applications — how it is or is not currently applied to child health services.
- Develop a better understanding about what is actually in place and functioning.
- Develop greater appreciation for perceptions of people from different disciplines, departments, and agencies.
- Learn that the perceptions of families may be the same as staff or may be quite different.
- Develop an appreciation for the collaborative process.

Another benefit of the assessment process is that it develops mutual support, understanding, and respect among people who have traditionally not worked together. These new relationships set the stage for future collaborative efforts.

In the assessment process, many positive features of programs and services as well as areas for change may be identified. Through a comprehensive assessment, priorities can be set that are realistic for a particular agency or program. For example, it may be very clear that the informational materials for families about injury prevention or emergency services are inadequate; staff development programs for out-of-hospital providers should be improved; ED policies and procedures need to be changed regarding family participation in care; or disaster planning needs to be strengthened. An action plan can be developed and collaborative work groups appointed to address these issues specifical-

ly. It is important to remember not to tackle the more complex and difficult issues first. Begin with tasks that have potential for success fairly quickly, thus building credibility and momentum for positive change.

The assessment tools can be used more than once. They can serve as tools for monitoring progress. However, it should be noted that sometimes scores go down in a follow-up assessment before they rise because the understanding of family-centered care and its practical applications has developed further.

In Summary

Family-centered care requires creative thinking, honest dialogue, and a willingness to support innovations in health care practice. It implies careful review of the roles, rights, and responsibilities of families and providers, as well as an examination of individual attitudes and organizational culture.

This document discussed family-centered concepts and how they are currently being applied to emergency services. It described ways to identify and involve families in a process of change, and provided suggested activities and structures to begin this process. Prior experience tells us that family-centered change in emergency services will be most effective when you:

- Start with potentially successful, easy steps.
- Look for family leaders and others interested in promoting change and get them involved in planning, implementation, and evaluation.
- Learn to see services and the system of care through the eyes of children and families
- Create opportunities for dialogue with families in planning for emergency, critical care, and disaster situations.
- Anticipate and prepare proactively for challenging situations — developing detailed plans and procedures to ensure that families receive the information and support they want and need.
- Commit to a long-term staff development program that includes dialogue and experiential learning to build family-centered skills in staff at all levels. Involve families in curriculum development and as faculty.

Appendix A: Building Family-centered EMS at the State Level: A Self-assessment Inventory

This assessment tool has been developed to assist EMS agencies, federally funded EMSC grantee, and families/consumers served by EMS agencies in improving statewide emergency medical services for children and families. It is designed to help you think through how families are involved in the design, delivery, and evaluation of your statewide system of emergency medical services. It will promote understanding of how family-centered concepts can be applied in systems development, policies, programs, procedures, and practices of the EMS agency or grantee. It can aid in the development of annual operating plans or a multi-year strategic plan. It can also serve as a framework for establishing short and long-term goals, prioritizing the next steps in an action plan, or initiating an ongoing process of change. Consider using it to shape continuous quality improvement.

The priorities for and capacities of EMS in each state vary tremendously. Therefore, individual states will use this tool somewhat differently, responding to their own needs, priorities, concerns, and resources as they develop quality, cost-efficient systems of care.

Instructions

Assemble an interdisciplinary, multi-perspective team that includes families whose children have experienced emergency care. In preparation for the meeting, ask each member to read *Working with Families to Enhance Emergency Medical Services for Children*. Some teams have found it helpful to have individuals complete the tool and then to meet as a group, discuss responses, and formulate a collective response. We recommend setting aside two to three hours for the team to complete and discuss this checklist.

Respond to each item individually. The "examples/comments/ideas for change" section is for you to write remarks, raise issues, or list examples that illustrate how family-centered concepts are applied in your agency's policies, programs, procedures, and practices. This section also encourages you to present your own ideas for change. Use the priority column to indicate which issues should be addressed first. At the end of the inventory are a number of open-ended questions that should also be discussed.

Key Questions				
	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are families, especially those whose children have experienced emergency care, involved at the state level in policy formulation and program planning and evaluation? <ul style="list-style-type: none"> • Do these consumers represent a range of emergency care experiences? • Do they reflect diverse backgrounds and cultures? 				
2. Are local and regional EMS entities encouraged to involve families in policy formulation and systems planning and evaluation?				
3. Do EMS committees and task forces have consumers as members?				
4. Does EMS leadership demonstrate its understanding of the vital roles that families play in the development of emergency medical services for children and in the care of an individual child?				

Key Questions

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • Are family-centered principles reflected in how the vision for EMS is communicated throughout the state? • Do EMS leaders serve as role models at the state, regional and local levels by reaching out and involving families as partners in building systems of care? • Do leaders appoint or encourage the appointment of consumers of children's emergency services to committees, task forces, and teams? 				
<p>5. Are families involved in:</p> <ul style="list-style-type: none"> • developing the pediatric components of the statewide EMS system? • injury prevention initiatives? • review of dispatch questions and pre-arrival instructions for clarity and effectiveness? • fundraising? • shaping state legislative and regulatory initiatives? 				
<p>6. Are families involved in educating EMS professionals about:</p> <ul style="list-style-type: none"> • consumer expectations? • family-centered principles? • opportunities for and benefits of family/professional collaboration? • sharing information with families? • various ways to support children and families? • effective interpersonal communication? • cultural competence? • specific childhood disabilities? 				
<p>7. Are families involved in public awareness and media activities, such as:</p> <ul style="list-style-type: none"> • participating in press conferences? • contributing to public service announcements (PSAs)? • developing and submitting articles and letters to editors? 				
<p>8. Are families involved in the collaborative process of developing and/or review-</p>				

Key Questions

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>ing protocols for addressing the needs of children and families:</p> <ul style="list-style-type: none"> • at the scene? • during transport? • for referrals, follow-up information, and care? • for bereavement and support? 				
<p>9. Are there rules or policies in your state that encourage the following practices:</p> <ul style="list-style-type: none"> • respecting a family member's desire to ride along with a child in an ambulance? • respecting a family member's desire to provide care or remain with the child during procedures and resuscitation? • having communication guides or fact sheets available to use with non-English speaking, deaf, and/or hearing impaired children and families? • learning the languages of communities served by EMS? • including families in the development of a DNR protocol? • including families in the development of a bereavement protocol? 				
<p>10. Is there a system in place within your state that supports EMS providers in making referrals to services and supports that families might need, such as:</p> <ul style="list-style-type: none"> • primary care? • social services? • mental health services? • substance abuse treatment? • child abuse prevention and treatment, including sexual abuse? • domestic violence prevention and treatment? • conflict resolution programs? • family support networks? • information clearinghouses and web sites? • parenting education? 				
<p>11. Are there outreach initiatives within the state to identify families of children with special needs who may need specialized emergency services?</p>				

Key Questions

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • Do local EMS providers and emergency departments develop plans proactively for specific children with special health care needs or disabilities within their service areas? • If yes, do they work with families in developing emergency care plans? 				
12. Has the emergency medical services organization in your state developed partnerships with community-based and family-led organizations to meet the health and safety needs of children and families?				
13. Are families involved in continuous quality improvement initiatives for the state's emergency medical system?				
14. Does EMS at the state level provide continuing education for pediatric emergency care and family-centered approaches to care?				

15. Are there other ways that your state's EMS agency demonstrates a commitment to family-centered care?

16. What are the biggest challenges your state's EMS agency faces in implementing family-centered care (e.g., identifying families to serve in advisory capacities, attitudes of staff and volunteer professionals, cut-backs in funding and personnel)?

17. What are the opportunities for family-centered change in your organization?

18. How might the involvement of families enable agencies in your state to respond effectively to challenges presented by the ways health care is being financed today (e.g. managed care, Medicaid, etc.)?

19. What are the 3-5 top priorities for family-centered change in your state's EMS organization?

Note: This tool was developed by the Institute for Family-Centered Care in collaboration with the EMSC National Resource Center with support from the U.S. Department of Health and Human Services' Health Resources and Services Administration, Maternal and Child Bureau grant # MCJ-247058.

Appendix B: Developing Family-centered EMS at the Local Level: A Self-assessment Inventory

This tool was developed to assess public and private ambulance companies, fire departments, local and county health departments, hospitals that provide EMS services, and other local EMS agencies. Administrative leaders should use it to help facilitate discussions with local advisory boards, EMT's and paramedics, and families/consumers served by the EMS organization. The self-assessment is a comprehensive inventory, organized across multiple dimensions, that outlines a vision for the organization from the perspective of being responsive to the needs and priorities of children and families.

The tool is divided into the following eight sections and ends with several open-ended questions:

- Vision, Mission and Philosophy of Care
- Family Participation in Care
- Family Support
- Information and Decision Making
- Service Coordination and Continuity
- Personnel Practices
- Evaluation/ Continuous Quality Improvement
- Community Partnerships

This assessment will help you think about family-centered care in relation to the policies, programs, procedures, and practices of your organization. It can aid in the development of annual operating plans or a multi-year strategic plan. It can also serve as a framework for establishing short and long-term goals, prioritizing the next steps in an action plan, or initiating an ongoing process of change. Consider using it to shape continuous quality improvement initiatives and staff development activities.

EMS organizations within and across communities vary tremendously in their capacities and resources. Thus each will use the tool somewhat differently, responding to its own needs, concerns, priorities, and resources and those of the community at large.

Instructions

This tool is designed for use by an interdisciplinary team that includes several family members whose children have experienced emergency care. Your team can choose to work on selected sections or complete the entire checklist. In either case, your team should discuss each item and decide on one team response. Some teams have found it helpful to have individuals complete the tool and then to meet as a group, discuss responses, and formulate a collective response. We recommend setting aside two to three hours for the team to complete this checklist. The team may find it helpful to read *Working with Families to Enhance Emergency Medical Services for Children* prior to completing the checklist.

Respond to each item individually. The "examples/comments/ideas for change" section is for you to write remarks, raise issues, or list examples that illustrate how family-centered concepts are applied in your agency's policies, programs, procedures, and practices. This section also encourages you to present your own ideas for change. Use the priority column to indicate which issues should be addressed first.

Vision, Mission, and Philosophy of Care				
	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Is there a vision and/or mission statement for the EMS organization?				
2. Is there a statement of philosophy or core values that: <ul style="list-style-type: none"> • acknowledges the pivotal roles of families in promoting the health and well-being of their children? 				

Vision, Mission, and Philosophy of Care

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • articulates the core concepts of family-centered care? <ul style="list-style-type: none"> - respect - strengths - choice - flexibility - information - support - collaboration - empowerment <p>3. Were families served by the EMS organization involved in developing the philosophy of care statement?</p>				
4. Is this philosophy of care reflected in the EMS organization's operating procedures, staffing patterns, and strategic plan?				
5. Is this philosophy of care statement communicated to families and throughout the community?				

Family Participation in Care

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Do all EMS providers recognize families as important sources of information about their children and their children's conditions?				
2. Are policies in place that are flexible enough for a family to decide who stays with the child during treatment, including resuscitation, and transport?				
3. Are families encouraged to provide care to their children in an emergency situation and during transport?				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Do all EMS providers, in the way they deliver services, effectively promote and support family/child relationships?				
<p>2. Do EMS providers help and support families at the following times:</p> <ul style="list-style-type: none"> • when EMS first arrive? • as the family waits for information? • following the death of a child or other crisis events? 				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
3. Do all EMS providers view interactions with families as opportunities to support families in the care and nurture of their children?				
4. Do EMS providers interact respectfully with all families? • Do they view all families as having strengths and competencies?				
5. Are resources such as communication guides or fact sheets available to support children and families who do not speak English or who are deaf or hearing impaired: • on the scene? • at dispatch? • at the hospital?				
6. Are maps and other helpful information available to the family when a child is transported to a hospital or other health care facility?				
7. Is the privacy of families protected during and after an emergency incident?				
8. Does the organization have a bereavement team and protocol?				

Information and Decision Making

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are explanations and information updates provided to the family whether or not they are with the child?				
2. Are families provided with information about possible roles they can play during a crisis situation?				
3. Are families provided, in a timely manner, the information and support they need to make decisions about their child's treatment?				

Information and Decision Making

	Yes	No	Examples/Comments/Ideas for Change	Priority
4. Are parents' choices and decisions about their child's care respected and honored by EMS providers?				
5. Is there a process for resolving conflicts between families and providers? • Is information about this process shared with families?				
6. Is public information and education provided to families to prepare them for emergency situations?				
7. Are educational materials: • available in the primary languages of the communities served by the EMS organization? • written at approximately a fifth grade reading level? • available in audiovisual formats?				

Service Coordination and Continuity

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are EMS providers supported and encouraged in making referrals to the following services that families might need: • social services? • primary care? • mental health services? • substance abuse treatment? • child abuse prevention and treatment programs, including sexual abuse? • domestic violence prevention and treatment programs? • conflict resolution programs? • law enforcement? • family-to-family support networks? • bereavement support? • funeral services? • organ donation? • parenting education? • information clearinghouses or web sites?				

Service Coordination and Continuity

	Yes	No	Examples/Comments/Ideas for Change	Priority
2. Are there outreach initiatives to identify families of children with special health care needs or disabilities who may need specialized emergency care in the EMS organization's service area?				
3. Does your organization have a relationship with hospital discharge planners and school nurses to anticipate emergency care that children with special health care needs or disabilities may require?				
4. Do local EMS providers develop plans proactively for individual children with special health care needs or disabilities within their service area? • If yes, do they work with families in developing these plans?				

Personnel Practices

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Do EMS personnel providing care to children have the clinical skills and experience needed to provide pediatric emergency care?				
2. Are EMS personnel providing care to children trained in working with children with special health care needs/disabilities and their families in emergency situations?				
3. Do EMS providers reflect the cultural and ethnic diversity of patients and families served by the agency?				
4. Are EMS providers encouraged to learn the languages of the communities they serve?				
5. Do position descriptions and performance appraisals clearly articulate the importance of working in respectful, supportive, and collaborative ways with patients and their families?				
6. Are families who have experienced emergency medical services involved in				

Personnel Practices

	Yes	No	Examples/Comments/Ideas for Change	Priority
providing orientation and inservice programming for EMS providers?				
7. Do orientation and inservice programming include discussions about: <ul style="list-style-type: none"> • family-centered principles? • effective interpersonal communication? • cultural competence and overcoming linguistic barriers? • supporting children of all ages in developmentally appropriate ways? • Sharing medical and other information effectively with families? • opportunities for and benefits of family/professional collaboration? 				
8. Do orientation and inservice programming include discussions about applying family-centered principles: <ul style="list-style-type: none"> • when working with violent individuals? • in recognizing and reporting possible child abuse? 				
9. Are there opportunities for EMS providers to "debrief" and share feelings and concerns after critical incidents?				
10. Are there recognition and appreciation initiatives for EMS providers?				

Evaluation/Continuous Quality Improvement

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are family members involved in the development of the consumer satisfaction system and in collection and analysis of information about family satisfaction with EMS policies and programs?				
2. Are family members involved in responding and finding solutions to the ideas, suggestions, and concerns expressed by families?				
3. Is there a family advisory committee or family/professional advisory committee for the organization?				

Evaluation/Continuous Quality Improvement

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • Are families on this committee representative of the diversity of families and health care conditions served? 				

Community Partnerships

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are families and family-led organizations involved in community outreach efforts?				
2. Do families participate in the organization's: <ul style="list-style-type: none"> • injury and violence prevention efforts? • public awareness and media events? • fundraising activities? • public policy initiatives? 				

Additional Questions:

1. Are there other ways that your EMS organization demonstrates a commitment to family-centered care?

2. What are the biggest challenges your EMS organization faces in implementing family-centered care (e.g., identifying families to serve in advisory capacities, attitudes of EMS providers, cut-backs in personnel)?

3. What are the opportunities for family-centered change in your EMS organization at this time (e.g., a public awareness campaign, a new continuous quality improvement initiative)?

4. How might the involvement of families in shaping emergency services enable your EMS organization to respond more effectively to challenges presented by the ways health care is financed today (e.g., managed care, Medicaid, etc.)?

5. What are the 3-5 top priorities for family-centered change in your EMS agency?

Note: This tool was developed by the Institute for Family-Centered Care in collaboration with the EMSC National Resource Center with support from the U.S. Department of Health and Human Services' Health Resources and Services Administration, Maternal and Child Bureau, grant # MCJ-247058.

Appendix C: Family-Centered Care in the Emergency Department: A Self-assessment Inventory

This assessment tool has been developed to promote thinking about family-centered care in relation to the policies, programs, practices, and environments affecting children treated in an emergency department. It is a comprehensive inventory, organized across multiple dimensions, that outlines a vision for emergency department services from the perspective of being responsive to the needs and priorities of children and families.

The checklist is divided into the following nine sections and ends with several open-ended questions:

- Vision, Mission and Philosophy of Care
- Family Participation in Care
- Family Support
- Information and Decision Making
- Service Coordination and Continuity
- Personnel Practices
- Environment and Design
- Evaluation/ Continuous Quality Improvement
- Community Partnerships

The tool provides a framework for an in-depth review of an emergency department. It is intended to facilitate discussion and collaboration among administrative and clinical leaders within hospitals, “front-line” staff, and families served by the emergency department. It can aid in the development of annual operating plans or a multi-year strategic plan. It can also serve as a framework for establishing short and long-term goals, prioritizing the next steps in an action plan, or initiating an ongoing process of change. Consider using it to shape continuous quality improvement initiatives and staff development activities.

State health agencies and federal EMSC grantees striving to enhance emergency services for children within their states might consider using this tool in the following ways:

- Create a task force of consumers and representatives of hospital emergency departments interested in completing the inventory within their hospital and then meet to discuss issues and strategies that might be mutually beneficial across various hospital settings within the state.
- Distribute the tool to individual hospitals serving significant numbers of children and suggest that they complete the tool.
- Describe the tool and its uses in grantee newsletters or state meetings and offer to assist emergency departments interested in completing this self-assessment.

Hospitals vary tremendously in their capacities and resources. Each will use the tool somewhat differently, responding to its own needs, priorities, and resources and those of the community at large.

Instructions

This tool is designed for use by an interdisciplinary team that includes several family members whose children have experienced emergency care. Your team can choose to work on selected sections or complete the entire checklist. In either case, your team should discuss each item and decide on one team response. Some teams have found it helpful to have individuals complete the tool and then to meet as a group, discuss responses, and formulate a collective response. We recommend setting aside two to three hours for the team to complete this checklist. The team may find it helpful to read *Working with Families to Enhance Emergency Medical Services for Children* prior to completing the checklist.

Respond to each item individually. The “examples/comments/ideas for change” section is for you to write remarks, raise issues, or list examples that illustrate how family-centered concepts are applied in your emergency department’s policies, programs, practices, and environment. This section also encourages you to present your own ideas for change. Use the priority column to indicate which issues should be addressed first.

Vision, Mission, and Philosophy of Care

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Is there a vision and/or mission statement for the hospital?				
2. Is there a vision and/or mission statement specifically for the hospital's emergency department?				
3. Is there a statement of philosophy or core values that: <ul style="list-style-type: none"> • acknowledges the pivotal roles of families in promoting the health and well-being of their children? • articulates the core concepts of family-centered care? <ul style="list-style-type: none"> - respect - information - strengths - support - choice - collaboration - flexibility - empowerment 				
4. Is this philosophy of care reflected in: <ul style="list-style-type: none"> • the emergency department's operating policies and procedures? • long term goals or strategic plan? 				
5. Is the philosophy of care statement communicated to families (e.g., posted where they can read it)?				
6. Were families served by the emergency department involved in developing the philosophy of care statement?				

Family Participation in Care

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Do emergency department staff recognize that families are important sources of information about their child and their child's condition?				
2. Are policies/procedures flexible enough for a family to decide for themselves if and who stays with their child: <ul style="list-style-type: none"> • during examinations? • invasive procedures? • critical care including resuscitation? 				

Family Participation in Care

	Yes	No	Examples/Comments/Ideas for Change	Priority
3. Are families encouraged to and supported in staying with their child, if this is their choice?				
4. Are families encouraged to provide support and to assist with care for their child in the emergency department?				
5. Are families provided information/ assistance on how to facilitate their child's coping during painful or stressful procedures: <ul style="list-style-type: none"> • age appropriate distraction techniques? • use of stress or anxiety reducing techniques? 				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Do emergency department staff, in the way they deliver services, effectively promote and support family/child relationships?				
2. Is staff or volunteer supervision provided for children in the waiting/lobby area? <ul style="list-style-type: none"> • If so, who provides the supervision? • Are there toys and/or other play materials available for children of all ages and abilities in the waiting/lobby area? 				
3. Are developmentally appropriate activities provided to children prior to, during, and after procedures?				
4. Do staff view interactions with families as opportunities to support families in the care and nurture of their child?				
5. Do staff interact respectfully with all families? Do staff view all families as having strengths and competencies?				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>6. Are the following available to support children and families in the emergency department 24 hours/day:</p> <ul style="list-style-type: none"> • translators/interpreters? • sign language interpreters? • child life specialists? • social workers? • chaplains? • mental health professionals? • patient representatives/family liaisons? • security personnel? 				
<p>7. What assistance and support are available to the family when a child is transferred to another facility?</p> <p>Is at least one family member permitted to accompany the child in the transport vehicle:</p> <ul style="list-style-type: none"> • ground ambulance? • helicopter? • fixed wing? 				
<p>8. Are staff members available to help and support families at the following times:</p> <ul style="list-style-type: none"> • when they first arrive in the emergency department? • as they wait for routine care and information? 				
<p>9. Is there a procedure for initiating family support during a crisis or life-threatening situation?</p>				
<p>10. Are staff outside of the emergency department utilized to provide family support?</p> <p>If yes, is this support available 24 hours/day?</p>				
<p>11. Are the following considered crisis events that trigger family support procedures in the emergency department:</p>				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • the diagnosis of a serious illness or impairment? • admission to the hospital? • transfer to another facility? • trauma team activation or trauma resuscitation? • cardiac and/or respiratory arrest? • critical illness? • death? 				
<p>12. In trauma and other crisis or life-threatening situations, are frequent information updates (every 5 to 10 minutes) provided to the family when they are outside the room as well as when they are present with the child?</p> <p>Is a specific individual designated to coordinate the exchange of information with the family?</p> <p>Does this individual remain involved as a support person throughout the crisis or resuscitation?</p>				
<p>13. Is privacy provided for families coping with stressful events such as admission to a critical care unit or transfer to a pediatric center?</p>				
<p>14. Are families with a child on a DNR protocol provided support and privacy? Are staff that are involved with the family on an ongoing basis notified that the child is in the emergency department? Do those staff assist with the emergency department care and disposition plan?</p>				
<p>15. Is privacy provided for families coping with the death of a child?</p>				
<p>16. Does the emergency department have a bereavement team and/or protocol with information and care specific to the loss of a child?</p> <p>Are mementos (i.e., lock of hair, footprints, handprints, memory box, etc.) provided/offered to the parent?</p>				

Family Support

	Yes	No	Examples/Comments/Ideas for Change	Priority
Is there follow-up with the family at a specified interval of time following the child's death?				

Information and Decision Making

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>1. Does pediatric bereavement information include:</p> <ul style="list-style-type: none"> • information on grief responses? • hospital and community bereavement support groups? • information on funeral services, planning a service, and available community resources? • information on organ/tissue donation, if appropriate? • information on autopsy and release of the body from the hospital and/or medical examiners? • names of staff who provided care in the emergency department? • telephone number of a contact person at the hospital if the family has questions after discharge? 				
2. Are families provided, in a timely manner, the information they need to make decisions about their child's treatment?				
3. Are families asked how they would like medical and other information provided to them?				
4. Are parents' choices and decisions about their child's care respected and honored by staff?				
5. Is there a process for resolving conflicts between families and providers? Is information about this process shared with families?				
6. Is there an ethics committee available to families and staff?				
7. Do family members serve on the ethics committee?				

Information and Decision Making

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>8. Are families given information about follow-up care for their child and pharmaceutical and other supplies or equipment they may need?</p> <p>Is this information in writing?</p> <p>Is this information available in the primary languages of the communities served by the hospital?</p> <p>Is this information written at approximately a fifth grade reading level?</p> <p>Is essential information available through another medium for families who cannot read?</p> <p>Is someone available on-site to assist with complex discharge situations?</p>				
<p>9. Does the emergency department support parents in reading or understanding their children's charts?</p>				
<p>10. Does the emergency department support families in obtaining information through:</p> <ul style="list-style-type: none"> • educational materials in the emergency department? • access to translators/interpreters? • access to a family resource library? • the medical library? • the Internet, information clearinghouses, or web sites? 				

Service Coordination and Continuity

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>1. Is a staff member assigned to assure that care is coordinated during the emergency department visit?</p>				
<p>2. Is there communication with the child's primary care provider during or after an emergency department visit?</p>				

Service Coordination and Continuity

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>3. Is information provided and/or referrals made consistently to services families might need:</p> <ul style="list-style-type: none"> • social services? • primary care provider? • mental health services? • child abuse prevention and treatment programs? • substance abuse treatment? • domestic violence prevention and treatment programs? • parenting education? • pastoral care? • home health care? • equipment suppliers? 				
<p>4. Is there a mechanism in the hospital to make referrals for specialized services such as:</p> <ul style="list-style-type: none"> • family-to-family support networks, including those relating to special needs/disabilities? • rehabilitation resources? • respite care providers? • specialized child care? • early childhood intervention services? 				
<p>5. Do staff help families of children with special health care needs or disabilities develop an emergency plan if one is not in place?</p> <p>If yes, do they collaborate with the child's primary care provider or subspecialist?</p>				

Personnel Practices and Training

	Yes	No	Examples/Comments/Ideas for Change	Priority
<p>1. Do staff providing care to children have the clinical skills and experience needed to provide pediatric emergency care?</p>				
<p>2. Do staff receive initial orientation and/or ongoing training on the following topics:</p>				

Personnel Practices and Training

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • growth and development? • supporting and preparing children in developmentally appropriate ways for painful and/or stressful procedures? • pediatric pain management and sedation? • non-pharmacologic pain management techniques? • techniques for positioning for procedures? • recognition and management of pediatric emergencies? 				
<p>3. Does orientation and/or inservice programming include discussions about:</p> <ul style="list-style-type: none"> • family-centered principles? • effective interpersonal communication? • cultural competence and overcoming linguistic barriers? • sharing medical and other information with families? • opportunities for and benefits of family/professional collaboration? 				
<p>4. Are staff trained in working with families and children with special needs/disabilities in emergency situations?</p>				
<p>5. Do staff and volunteers reflect the cultural and ethnic diversity of patients and families served by the hospital?</p>				
<p>6. Are staff encouraged to learn the languages of the primary communities served?</p>				
<p>7. Do position descriptions and performance appraisals clearly articulate the importance of working in respectful, supportive, and collaborative ways with patients and their families?</p>				
<p>8. Are families who have experienced emergency care involved in providing orientation and/or inservice programming for staff?</p>				

Personnel Practices and Training

	Yes	No	Examples/Comments/Ideas for Change	Priority
9. Is there sufficient space for staff support, including a staff lounge accessible for frequent short breaks?				
10. Is there a staff support group or other regularly occurring opportunity for peer support?				
11. Are there opportunities for staff to debrief and share feelings and concerns after critical incidents?				
12. Are there staff recognition and appreciation initiatives?				

Environment and Design

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Does signage, both outside and inside the hospital, clearly indicate the route to the emergency department?				
2. Is all signage understandable to families who do not read? Who do not read English?				
3. Is parking convenient to the emergency unit and affordable for families?				
4. Is the waiting area large enough, with enough comfortable seating available, for all children and adults who may be waiting, even if several adults and children accompany one child? <ul style="list-style-type: none"> • Does seating accommodate children and adults with special needs or assistive devices? • Does seating accommodate children who do not feel well enough to sit up? 				
5. Is there an observation unit or holding area? <ul style="list-style-type: none"> • Does it provide space and support for families who choose to remain with their children? • Are the needs of accompanying children (brothers and sisters, friends) addressed? 				

Environment and Design				
	Yes	No	Examples/Comments/Ideas for Change	Priority
6. If pediatric emergency care is provided in the same unit with adult care, are the pediatric waiting and examination areas visually and acoustically separated from the adult area?				
7. Can families easily find their way from the emergency room to other areas in the hospital, such as: <ul style="list-style-type: none"> • radiology? • laboratories? • pharmacy? • admitting office? • patient care units? • cafeteria? 				
8. Are telephones, rest rooms with diaper changing areas, water fountains, ATM machines, vending machines, and breast feeding rooms convenient to the emergency department? <ul style="list-style-type: none"> • Are services clearly marked in the primary languages of the communities served by the hospital? • Do families have access to telephones that are free of charge and located in private areas? 				
9. Are examination, treatment, and procedure rooms designed to accommodate parents who wish to remain with their child?				
10. In examination, treatment, and procedure rooms, is there adequate closed storage for equipment and supplies that can potentially frighten children?				

Environment and Design				
	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Are there a variety of ways for families to provide information about their perceptions of care in the emergency department, such as: <ul style="list-style-type: none"> • written surveys? • follow-up phone calls? 				

Environment and Design

	Yes	No	Examples/Comments/Ideas for Change	Priority
<ul style="list-style-type: none"> • suggestion boxes? • participation on emergency department committees or task forces? • discussion groups? • hospital committees and task forces? 				
2. Are families involved in the development of the consumer satisfaction system for the emergency department?				
3. Are family members involved in responding and finding solutions to the ideas, suggestions, and concerns expressed by families?				
4. Is there a family advisory committee or family/professional advisory committee for the emergency department? Are families on this committee representative of the diversity of families and health care conditions served by the hospital?				

Community Partnerships

	Yes	No	Examples/Comments/Ideas for Change	Priority
1. Has the hospital and/or the emergency department developed partnerships with community organizations to meet the health and safety needs of children and families?				
2. Are families and family-led organizations involved in community outreach efforts?				
3. Do families participate in the hospital's: <ul style="list-style-type: none"> • injury and violence prevention efforts? • public awareness and media events? • fundraising activities? • public policy initiatives? 				

Appendix D: Community-based Advocacy Organizations

For help in building a more family-centered system of care and in identifying families to serve as advisors, contact:

EMSC National Resource Center

111 Michigan Avenue, NW
Washington, DC 20010-2970
(202) 884-4927
(202) 884-6845 FAX
www.ems-c.org
e-mail: info@emscnrc.com.

Institute for Family-Centered Care

7900 Wisconsin Avenue, Suite #405
Bethesda, MD 20814
(301) 652-0281
(301) 652-0186 FAX
www.familycenteredcare.org
e-mail: institute@iffcc.org

Check out these publications produced by the Institute for Family Centered Care:

- *Essential Allies: Families as Advisors*
- *Words of Advice: A Guidebook for Families Serving in Advisory Roles*
- *Families as Advisors: A Training Guide for Collaboration*

For information about injury prevention and families involved in these efforts, contact:

National SAFE KIDS Campaign

One Pennsylvania Avenue, NW
Washington, DC 20004
(202) 662-0600
(202) 393-2072 FAX
www.safekids.org

Think First Foundation

22 South Washington Street
Park Ridge, IL 60068
(847) 692-2740
(847) 692-2394
www.thinkfirst.org
e-mail: thinkfirst@aans.org

For information and resources on culturally competent health care, contact:

Office of Minority Health Resource Center

P.O. Box 37337
Washington, DC 20013-7337

(800) 444-6472
www.omhrc.gov
e-mail: lmosby@omhrc.gov

National Center for Cultural Competence

Georgetown University - Child Development Center
3307 M Street, NW, Suite #401
Washington, DC 20007-3935
(800) 788-2066 or (202) 687-5387
(202) 687-8899 FAX
www.dml.georgetown.edu/depts/pediatrics/gucdc/cultural.html
e-mail: cultural@gunet.georgetown.edu

For information about and to locate families through state Parent to-Parent Organizations, contact:

Beach Center on Families and Disabilities

4138 Haworth Hall
Lawrence, KS 66045
(913) 864-7600
www.lsi.ukans.edu/beach/
e-mail: betsy@pclink.com

For information about and to identify families of children with special needs who are interested or and have experience in issues pertaining to health care financing, contact:

Family Voices National Office

P.O. Box 769
Algodones, NM 87001
(888) 835-5669 or (505) 867-2368
(505) 867-6517 FAX
www.familyvoices.org
e-mail: kidshealth@familyvoices.org

For information about the involvement of families in public policy activities, such as Medicaid, managed care, and health care insurance access, contact:

Families USA

1334 G Street, NW
Washington, DC 20005
(202) 628-3030

(202) 347-2417 FAX
www.familiesusa.org
e-mail: info@familiesusa.org

To contact families serving in leadership roles in state health departments, contact:

The Association of Maternal and Child Health Programs

1220 19th Street, NW, Suite # 801
Washington, DC 20036
(202) 775-0436
(202) 775-0061 FAX
www.amchp.org
e-mail: info@amchp.org

For information about state Parent Training and Information Centers, contact:

Federation for Children with Special Needs

1135 Tremont Street, Suite #420
Boston, MA 02120
(800) 331-0688 or (617) 236-7210
(617) 572-2094 FAX
www.fcsn.org/home.htm
e-mail: fcsninfo@fcsn.org

For information about national, state, and local PTAs, contact:

National Congress of Parent-Teacher Associations

330 North Wabash, Suite #2100
Chicago, IL 60611
(800) 307-4PTA [307-4782] or (312) 670-6782
(312) 670-6783 FAX
www.pta.org/index.stm
e-mail: info@pta.org

For information about state and local chapters of Arc and reaching persons with disabilities, contact:

The Arc of the U.S. - National Headquarters Office

1010 Wayne Avenue, Suite #650
Silver Spring, MD 20910
(301) 565-3842
(301) 565-5342 FAX
www.thearc.org
e-mail: info@thearc.org

Other local organizations and groups that may be a resource for identifying families who have experienced emergency medical services include:

- Hospital Family Advisory Councils
- Boy Scouts and Girl Scouts
- Specific disability support groups for conditions such as Cystic Fibrosis, Down's Syndrome, Asthma, and SIDS
- Local volunteer organizations, such as the Junior League, Kiwanis, Rotary, and Optimist Clubs

About FAN: A Profile About the EMSC Family Advocacy Network



What Is the EMSC Family Advocacy Network (FAN)?

FAN is a national network of parents, family members, and consumers who share the desire to advocate for a better emergency and health system for children. Most members are already active in their state's Emergency Medical Services for Children (EMSC) program. However, FAN also welcomes those who are not currently active.

The Network's primary mission is to provide its members with opportunities to participate in the development and implementation of state and national EMSC initiatives.

How Do FAN Members Advocate for Children?

Parents, family members, and consumers play a significant role in this nationwide effort. For example, FAN members:

- Serve on state EMSC Advisory Boards.
- Educate policy makers about the important needs of children.
- Advocate for family-centered care policies in pre-hospital and hospital settings.
- Help raise awareness of pediatric emergency training and equipment needs in prehospital, hospital, and community settings, such as schools, pri-

mary care provider offices, rehabilitation centers, and child care programs.

- Assess a community's readiness for a pediatric emergency.
- Volunteer to assist with local injury prevention projects, such as car seat checks, bicycle safety programs, fire prevention education programs, and much more!

Who Is Eligible to Join FAN?

FAN membership is open to any individual who is active in their state's EMSC program or who is interested in participating in state or national FAN initiatives. To join, contact Jennifer Beery, MPH, state outreach coordinator for the EMSC National Resource Center, at (202) 884-6841 or jbeery@emscnrc.com.

EMSC program coordinators may refer family advocates to the EMSC National Resource Center, or family advocates may contact the Center directly. FAN members will be linked with their state's EMSC program and provided with orientation materials and other helpful advocacy-related "how-to" resources.

For More Information . . .

For more information about national EMSC activities and family-centered care, visit the EMSC web site at www.ems-c.org. Once there, click on "Family Information." For questions about FAN, contact Beery at the above number or write to: Jennifer Beery, EMSC State Outreach Coordinator, EMSC National Resource Center, 111 Michigan Avenue, NW, Washington, DC 20010.

What Is EMSC Doing to Promote Family-centered Care?



Listed below are examples of how the Emergency Medical Services for Children (EMSC) Program promotes and participates in the development of family-centered care principles:

- **EMSC Family Advocacy Network (FAN).** In 1999, the EMSC National Resource Center developed FAN to support the inclusion of parents and family representatives in EMSC Programs around the nation. FAN was introduced at the 2000 EMSC National Congress on Childhood Emergencies and has since reached a membership of more than 60 parent, consumer, and family representatives. As family-centered care continues to be a priority for all EMSC programs, it is anticipated that family involvement in FAN and EMSC programs will grow.
- **Workshops and educational sessions on family-centered care.** The Annual EMSC Grantee Meeting and the biennial National Congress on Childhood Emergencies each feature comprehensive workshops and/or educational sessions on family-centered care.
- **EMSC Parent Volunteer of the Year award.** Part of the National Heroes Award program, this award is given to a parent/family representative who has been a volunteer for a minimum of two years and has provided meritorious service that results in a

significant impact on the emergency medical needs of the children in his or her community. (Improving family-centered care and cultural competency are key goals for EMSC parent volunteers).

- **Family advocate involvement at the national and state level.** Family representatives serve on several task forces for the EMSC National Resource Center, including the product review team and the planning committees for the Annual EMSC Grantee Meeting and the National Congress on Childhood Emergencies. At the state level, family advocates have assisted EMSC programs with their public policy objectives, institutional policies, community projects, outreach to families, regional meetings, and much more. In addition, several state EMSC programs include parent advocates on their advisory councils.

- **EMSC web site.** The EMSC web site includes numerous resources and links related to families and family-centered care. To access the information, go to www.ems-c.org. Once there, click on the section "Family Information."

- **Technical assistance.** Technical assistance related to family involvement strategies, advocacy, and family-centered care is ongoing to EMSC grantees as well as to family advocates and FAN members.

For more information about national EMSC activities and family-centered care, contact Jennifer Beery, MPH, state outreach coordinator for the EMSC National Resource Center, at (202) 884-6841; jbeery@emscnrc.com. or write to: EMSC National Resource Center, Attn: Jennifer Beery, 111 Michigan Avenue, NW, Washington, DC 20010.

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