



A NEW WAY TO SUPPORT FAMILIES

Partnering with Your Local EMS Providers to Support Your Family

Welcome to the Missouri Developmental Disabilities Resource Center (MODDRC). You are receiving this packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview**
- **Best Practices**
- **Personal Stories**
- **Family Support, Advocacy, and Services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family to Family Health and Disability Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We provide opportunities for leadership development and volunteerism. We also seek to provide information and training to community agencies so that they can provide services to individuals with disabilities or special health care needs and/or their families. When contacting the MODDRC, you are connecting to staff with first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

MISSOURI FAMILY TO FAMILY RESOURCE CENTER
DISABILITY & HEALTH INFORMATION CENTER

Missouri Family to Family Disability & Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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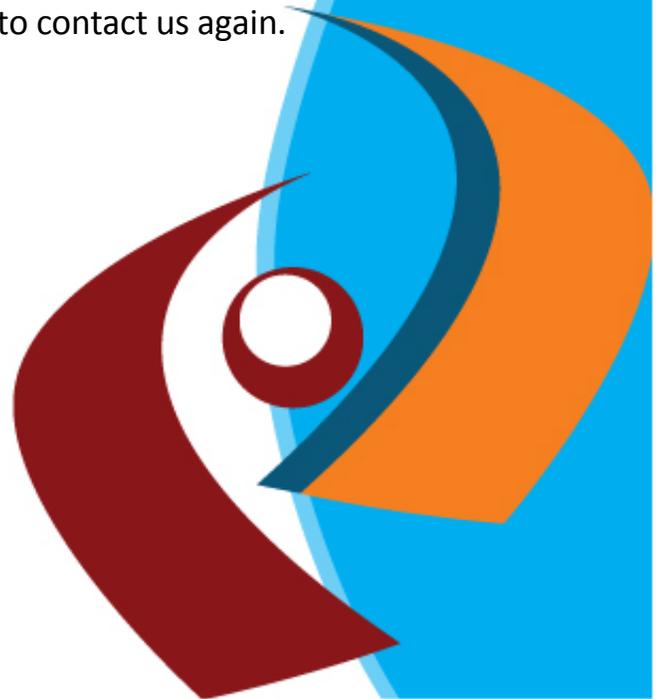
OVERVIEW



The purpose of this section is to help you gain a better understanding of a specific topic related to disability or special health care need. It is intended to provide a basic explanation of the topic and specific tips for success and may include:

- An overview of the topic
- Current practices
- Skills
- Tools

If you would like more information on this topic, please feel free to contact us again.



Overview: Emergency Medical Services



In an emergency, it is hard to think of everything:

- Do your emergency medical service providers know about the equipment your child uses in your home that depends on electricity? Do they know how your child communicates?
- Do you live in a rural area with few neighbors that could be difficult to reach?
- Do you have a plan for your other children if you need to ride to the hospital?

Emergency Medical Services (EMS) is more than a ride to the hospital, it is an organized system that provides emergency medical care.^{1,2} EMS systems include many people and agencies working together to provide fast emergency medical response, treatment, and transportation to people needing immediate medical attention.^{1,2} It provides personnel, facilities, and equipment to effectively coordinate delivery of emergency medical services within a geographical area.² It is the job of EMS to protect the public's health, safety, and welfare by assuring that the services provided meet or exceed established standards.³

Agencies responsible for providing EMS include:

- dispatch centers
- public safety agencies
- fire departments
- ambulance services
- police departments
- hospitals
- specialty care centers.

In the state of Missouri the system may look different depending on where you live, but there are some things that you can do to be prepared no matter where you live. We recommend meeting with the EMS providers in your area to introduce yourself and discuss your family's needs so they have necessary information before they arrive in an emergency. At this meeting you can give service providers information about your specific family needs and ask questions that you may have for them.

For help finding more information about this or other subjects, please contact our staff at the Missouri Family to Family Resource Center. We're here to help.

¹ What Is EMS? (2010). Retrieved May 26, 2010, from EMS.gov:

<http://www.ems.gov/portal/site/ems/menuitem.5149822b03938f65a8de25f076ac8789/?vgnnextoid=9990f44e90578110VgnVCM100002fd17898RCRD>

² Overview of EMS Systems (2010). Retrieved May 26, 2010, from:

http://www.acgov.org/ems/Resource/overview_of_ems_systems.PDF

³ Emergency Medical Services (2010). Retrieved May 26, 2010, from State of Missouri –Department of Health and Senior Services:

<http://www.dhss.mo.gov/EMS/>



BEST PRACTICES



On the following pages, you will find more information on supporting children and youth with special health care needs (CYSHCN) and their families from sources the MOF2F regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



Developing an Emergency Plan

It is important that you keep your medical information up to date in either a hard format, such as a binder, or electronically on a flash drive.

Thanks to new and advanced technology, more children with special health care needs are living at home than ever before, enabling them to participate more fully at school and in their communities. With this new independence comes a need to be well prepared for prompt, safe, specialized care in the event of a medical emergency. Families, caregivers, school officials and community leaders all need to share and collaborate in this responsibility.

The Emergency Medical Services for Children (EMSC) Program encourages parents (or guardians) and caregivers of children with special health care needs to develop a written emergency care plan and have it in plain sight, ready to go. This way, if and when an emergency occurs, family members, caregivers, bystanders, school nurses, teachers, and emergency medical services (EMS) providers will have the information they need to effectively initiate care — and possibly save a life. An emergency care plan is also a valuable resource for other health care providers, such as emergency room doctors and nurses and rehabilitation specialists.

Developing an Emergency Care Plan Is Very Important

Written emergency care plans should include brief but specific information about the child's medical condition, including physical and mental state. Parents and caregivers should work with their primary care physician, specialists, and case manager to develop a written emergency care plan that includes the following key information:

- Age
- Allergies (medications and food)
- Medical condition (diagnoses and relevant past medical history)
- Medications currently taking and medications to avoid
- Baseline findings (pulse and respiratory rates, blood pressure, orientation, etc.)
- Emergency intervention strategies (emergency procedures that best address your child's unique needs)
- Parent/caregiver information (names, phone numbers, addresses, etc.)
- Insurance information
- Primary care physician and specialists information (names, phone numbers, etc.)

The plan needs to be verified and signed by the child's parent or legal caregiver and primary or specialty physician. Copies of this document should be placed in several locations (e.g., near the kitchen telephone, in the child's bedroom, in the car, and at work).

It also is important that parents and caregivers work with school nurses and local EMS personnel to ensure that this confidential information is quickly and easily available at school, child care, and recreation programs. If a child is active and independent at school and away from home, he or she may want to carry the plan in his or her backpack, wallet, or purse.

Peace of Mind Is Only a Step Away

Developing an emergency care plan is an important step in caring for a child with special health care needs. It can give the child more freedom — and it can give parents and caregivers the peace of mind that comes with knowing their child is well cared for during a medical emergency. Be prepared, plan today.

Information courtesy of EMSC National Resource Center <http://www.emsc-c.org>

Using the Emergency Information Form

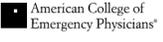
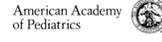
During an emergency, obtaining an adequate history for a child with special health care needs (CSHCN) may be difficult or time-consuming. For some children, documentation regarding all of their “special needs” may not be readily available.

An Emergency Information Form (EIF) was developed jointly by the American Academy of Pediatrics and the American College of Emergency Physicians and is available to relay that special information. It is completed by the child’s primary care physician and then given to the parent, child care provider, school nurse, and/or EMS provider to keep on file.

As a parent, you can do the following to facilitate the use of this form:

- Ask your child’s pediatrician to complete the form and give you a copy. Work with your child’s physicians and specialists to keep the form up to date when new medications are added, surgical procedures are done, etc.
- Give a copy to the local ambulance service and to any other caregivers responsible for your child.
- Work with discharge planners at the hospital to help with integration of your child back in the community.
- Keep copies of the form at your home/office.
- Work with school nurses in your community to identify and manage health and safety issues for your child.

Information courtesy of Pediatric Alliance
<http://www.pediatricalliance.com>.

Emergency Information Form for Children With Special Needs				
 American College of Emergency Physicians*	 American Academy of Pediatrics			
Name:		Birth date:	Nickname:	
Home Address:		Home/Work Phone:		
Parent/Guardian:		Emergency Contact Names & Relationship:		
Signature/Consent*:				
Primary Language:		Phone Number(s):		
Physicians:				
Primary care physician:		Emergency Phone:		
		Fax:		
Current Specialty physician: Specialty:		Emergency Phone:		
		Fax:		
Current Specialty physician: Specialty:		Emergency Phone:		
		Fax:		
Anticipated Primary ED:		Pharmacy:		
Anticipated Tertiary Care Center:				
Diagnoses/Past Procedures/Physical Exam:				
1.		Baseline physical findings:		
2.				
3.		Baseline vital signs:		
4.				
Synopsis:		Baseline neurological status:		

Last name:

*Consent for release of this form to health care providers

Communication Is the Key to Saving a Life

It is important that parents and caregivers take the time to introduce themselves and their children to their local EMS team. This initial introduction will help everyone learn more about the child's special needs — and feel more confident and secure in the event of an emergency.

In addition, children at risk for medical emergencies should consider wearing a medical bracelet or necklace to help emergency providers quickly recognize that the child has a special need. Until the medical personnel can access the child's written emergency care plan, it is important that they have a general sense of the child's condition.

When working with EMS it is also important that you work together with your school. This way, if there is an emergency at school during a school activity; EMS providers and school personnel can work together and be prepared to meet the needs of your child.

Meeting with Your Local EMS Workers

Meeting with EMS workers for the first time may feel scary, but it doesn't have to be. EMS workers have knowledge and training in dealing with emergencies. You have knowledge and experience in caring for your child. Together you can be prepared for an emergency.

The first step is finding out who to contact. In some areas there is one provider for everyone, while in other areas services are provided at the local level. You may need to call a local fire chief to learn who provides EMS services in your community. Once you know who to contact, call and set up a meeting.

EMS workers don't need a full medical history, but it is helpful if you are able to provide background about your child's needs and diagnosis. It is also helpful if you are able to provide EMS workers with a floor plan of your home that includes the location of equipment, such as where oxygen is stored, and where the individual needing the greatest assistance is in your home. You should also provide them with a copy of the *Emergency Information Form* (EIF), developed by the American Academy of Pediatrics and the American College of Emergency Physicians, and a photograph of your child.

Calling 911

In the event of an emergency it is important to know how, when, and what to tell the dispatch operator. Following the instructions listed can save time and allow needed help to arrive more quickly.

- Try to stay as calm as possible.
- Listen to what the dispatch operator is asking you.
- Speak slowly and in a clear voice.
- Answer all of the questions from the dispatcher.
- STAY ON THE PHONE with the DISPATCHER until emergency help arrives and continue passing vital information that can be shared with providers in route to your location. Do not leave your child alone to be on the phone, either bring your child to the phone or the phone to your child so that you can monitor his/her condition and speak with the dispatcher at the same time.

The dispatcher will have questions for you. Do your best to answer them. Based on the information you provide the dispatcher may ask additional questions or provide you with information to guide you until help arrives.

- **Where** is your emergency? (Address or Location)
- **What** is the number from which you are calling?
 - This is important so that communication can be re-established if you are cut off.
 - Some e911 systems will record your telephone number
 - **What** is the situation/problem/emergency?
 - Be sure to describe the current situation and tell the dispatcher the nature of your child's disability or special health care need.
 - **What** is your name?
 - Is the person conscious/able to communicate?
 - If your child does not speak under normal circumstances, is he/she communicating as usual?
 - Is the person breathing?

Information courtesy of EMSC National Resource Center <http://www.emsc-c.org>

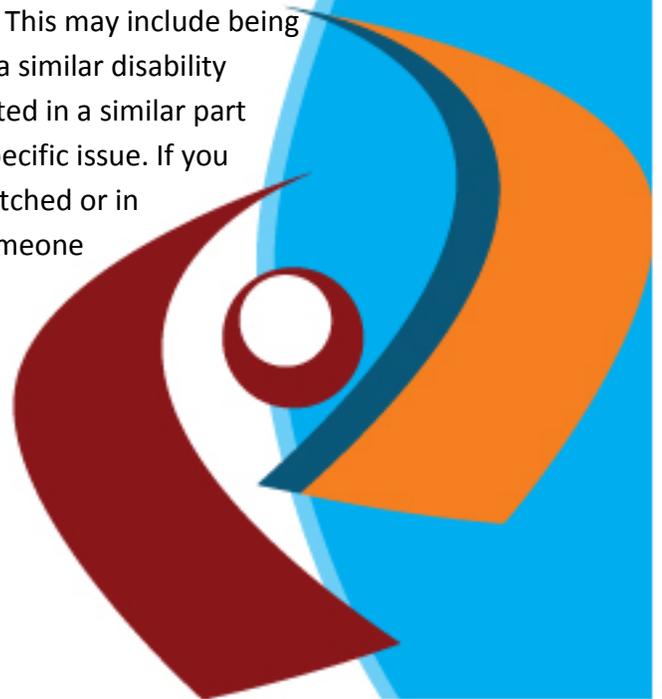


PERSONAL STORIES



This section will provide you with the perspective of parents, family members and those living with the disability or special health care need. Written personal stories are one way of connecting to others who have similar experiences. These stories give you insight on a specific experience including some of the joys and challenges that were experienced as well as suggestions.

Another way of connecting with others is through the Sharing Our Strengths peer support network. SOS provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.



How to Be Ready when Emergencies Happen

Beverly, mother of children with special health care needs

Working with EMS providers can be a lifesaving experience. We need to do whatever is necessary to meet the needs of our children in an emergency situation. When my son had to be life-flighted from Hannibal to Columbia, we couldn't ride in the helicopter with him. Because we had his information ready, they had everything that they needed and as soon as he was in the hospital I would be there. If people can be aware enough to do this in any given situation it is easier for the child and the family.



If you are new to an area or you've been there a while and your child is newly diagnosed, have EMS workers come to the house to get familiar with the area, child's room, emergency contacts, and location of stored supplies. I keep **posted** numbers on the refrigerator and our local department keeps information on file. It helps if workers can familiarize themselves with your child's diagnosis and needs (ex. getting out of bed, wandering, etc.) and know the family dynamics. Since some children's disabilities or health care needs are not visible, provide a picture of the child who may need assistance so that they know where to go first. I had workers come to my house, which was good when we had the fire. Although no one was home at the time, the first responders went through my son's bedroom window first because they knew where his bedroom was and that he would need assistance getting out.

My son also travels with a "**Keith** manual" that contains all of his emergency phone numbers, familiar things to him (a family picture, the front of our house, etc.), doctors' information, and current medication information in plastic sleeves so that we don't have to replace everything when his medication changes. This manual was helpful once when the bus he was riding was struck from behind. Even though there were no injuries he was taken to the local hospital where they could pull out the book and call me. Since my son is nonverbal, the book helped fill the communication gap.

EMS and local fire departments need to be involved. Get specific; give them a floor plan, because it's important to identify everything. Now when you call 911 you get everyone, but before you had to call and tell them who you needed. Make sure that you are familiar with your particular fire district and set up a time with your local fire chief so that everyone in route is familiar with your family and your child. You don't have to provide an entire health history. What truly makes a difference is knowing what to look for and how to communicate with that person. What they (EMS workers) need to do is help the child in the emergency situation, so arrange for your child to meet with EMS workers and see the ambulance, fire truck, police cars, etc. so that they are a **familiar faces and update as needed**. If you into a home and that child is the only one who is able to interact there has to be familiarity so that the children don't suffer a traumatic experience by being taken from their home. Most districts are willing to work with families. They prefer that you initiate and ask them to come. They are trained to do a job, but don't necessarily receive training for working with individuals with special health care needs or disabilities. Since they don't receive the education any assistance or education we can offer, even if it is just a half hour in our shoes can make a huge difference.



FAMILY SUPPORT ADVOCACY & SERVICES



This section will provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.





Support for Families

Missouri Family-to-Family Resource Center

Housed at the UMKC-Institute for Human Development, UCEDD

215 W. Pershing

Kansas City, MO 64108

Phone: 816.235.1763

Toll Free: 800.444.0821

web: <http://www.mofamilytofamily.org>

Missouri Family-to-Family is a statewide network of parents, family members, and individuals with disabilities and/or special health care needs providing information and peer support through the MOF2F Disability & Health Information Center and Sharing Our Strengths (SOS). SOS is a statewide support network of parents, family members, individuals with developmental disabilities and/or special healthcare needs, and professionals who are matched with peer mentors to share experiences, offer emotional support, and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.



MISSOURI

SERVICE SYSTEMS

The purpose of this section is to provide you with a listing of agencies focused on specific topics. This includes listing such as state or local agencies, hospitals, clinics, or education systems.



Support for Families

Individuals with special health care needs are those who have or are at increased risk for a disease, defect, or medical condition that may hinder the achievement of normal physical growth and development and who also require health and related services of a type or amount beyond that required by individuals general.

SHCN provides interpreter services (language or sign) for participants and/or family members. Alternate forms of this publication for persons with disabilities may be obtained by contacting the Missouri Department of Health and Senior Services. Services provided on a nondiscriminatory basis.

<http://www.dhss.mo.gov/FamilyPartnership>

Family Partners can be reached through the following agencies:

Special Health Care Needs (SHCN)

Missouri Department of Health and Senior Services
PO Box 570
Jefferson City, MO 65102-0570
Telephone (Toll-free): 800-451-0669
Fax: 573-751-6237 Email: info@dhss.mo.gov

Miller County Health Center

P.O. Box 2
Tuscumbia, MO 65082
Family Partnership Family Partnership
Toll-Free Number
1-866-809-2400, ext. 308

Emergency Medical Systems Contacts

Missouri Emergency Medical Systems Association provides contact information to regional board members.

425 East High Street
Jefferson City, MO 65101
Toll Free: 888-410-1557
<http://www.memsa.org>

Missouri EMS provides contact information for emergency response agencies.

9095 CR 410
Ellsinore, MO 63937
Telephone: (573) 998-2925
<http://missouriems.com>