Policy Statement—Emergency Information Forms and Emergency Preparedness for Children With Special Health Care Needs

abstract

Children with chronic medical conditions rely on complex management plans for problems that cause them to be at increased risk for suboptimal outcomes in emergency situations. The emergency information form (EIF) is a medical summary that describes medical condition(s), medications, and special health care needs to inform health care providers of a child’s special health conditions and needs so that optimal emergency medical care can be provided. This statement describes updates to EIFs, including computerization of the EIF, expanding the potential benefits of the EIF, quality-improvement programs using the EIF, the EIF as a central repository, and facilitating emergency preparedness in disaster management and drills by using the EIF. Pediatrics 2010;125:829–837

INTRODUCTION

Children with chronic medical conditions, including children with special health care needs, rely on multiple medications, medical technology devices, and complex management plans, which can cause them to be at increased risk of acute deterioration, medical errors, and suboptimal outcomes. Their conditions make them particularly vulnerable and prone to complications; therefore, they frequently rely on emergency care in the ongoing management of their special medical conditions. A detailed understanding of an individual’s special health care needs is required to provide optimal emergency care.1–9

When children with special health care needs access emergency medical services (EMS) or seek emergency care in a busy emergency or urgent care facility (or in the midst of a disaster), it is difficult for EMS personnel and/or the attending physician to review lengthy medical records (if they are available at all) and coordinate care with multiple specialty care providers. A summary describing their medical condition(s), medications, and special health care needs is necessary to reduce delays in diagnosis and treatment and facilitate greater efficiency in the provision of emergency care to children with special health needs. The transfer of traditional health-record information is slow and becoming more difficult for the following reasons:

1. Because of greater documentation requirements, health records are more comprehensive, which makes it more difficult to find important items related to the patient’s condition.
2. Delays are often caused by information-transfer consent requirements and misunderstandings surrounding the regulations of the Health Information Portability and Accountability Act (HIPAA).

3. Minimum necessary standards for release of information under HIPAA can interfere with gathering a complete set of pertinent information.

4. In a disaster scenario, the transfer of health records can be problematic because of an inability to access them, or paper records may be destroyed in the disaster.

The emergency information form (EIF) was proposed as a means to provide rapid access to a health summary for children with special health care needs in a 1999 joint policy statement (reaffirmed in 2002) by the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP). The EIF is a type of personal health record that was introduced as a concise, single-sheet summary designed to provide the essential information needed initially to treat a patient with special health care needs.

Experience since publication of the 1999 statement has identified the following:

- The EIF has been underused, because many health care providers and families of children with special health care needs are unaware of the EIF. Many providers consider EIF completion to be time-consuming and do not recognize the need for the EIF.

- The paper-based EIF is helpful but suboptimal for incorporation into electronic health records (EHRs) and for central repository access. A paper form physically limits the amount of information provided on the form and is not sufficiently adaptable for patients with a large set of problems. A computerized EIF can expand and adapt to the needs of the patient.

- The use of a computer-based EIF permits a central repository through which the EIF can be accessed remotely via the Internet rapidly. A capability to access a number of EIFs can also be built into such a system to facilitate a coordinated disaster response for children with special health care needs.

- Computerization of EIFs facilitates quality-improvement measures targeted at children with special health care needs and the use of the EIF.

- Computerization of EIFs facilitates the deployment of EIFs as a database that can be integrated into the EHR and can potentially be shared and networked between compatible hospitals and systems.

- A computerized EIF can accept templates or cut-and-paste management routines (clinical pathways) that are frequently recommended, such as the standard initial management of a child with tetralogy of Fallot.

- It should be noted that a computerized EIF might not be retrievable in the event of a power failure or damage to communication infrastructure (includes the Internet). An inkjet-printed paper document will smear: A water-resistant paper document or a “thumb drive” or compact disc containing the file in a plastic bag (together with insurance papers and other key documents) is more likely to be usable under certain disaster conditions.

### ADVANCING THE EIF TO A COMPUTER APPLICATION

- The computerized EIF can be easily updated with new information (eg, newly identified allergies, change in severity, addition of new problems, change in advance directives, change in specialists and their contact information) and provides an automated date stamp as to when it was most recently updated.

- The computerized EIF can be modified to accommodate system changes, such as legal requirements, immunization tables, and consents.

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### EXPANDING THE POTENTIAL BENEFIT OF THE EIF

- The process of initiating an EIF by the medical home and the patient’s specialists should include a review of likely emergencies and recommended therapies in the event of an acute exacerbation of the child’s chronic condition(s). This review enables subspecialists to recognize the difficulties faced by nonspecialists encountering their patients for the first time and facilitates the codification of initial management measures to improve communication with other care providers involved in the patient’s care. Examples of this include which laboratory tests should be ordered for a patient with an inborn error of metabolism, what type of intravenous fluid should be started, and whether the patient should be fed or kept off oral intake (NPO).

- Because EIF use is not yet routine, quality-improvement programs should target EIF initiation and
The percentage of children with special health care needs with an EIF in a practice can be audited by dividing the number of EIFs in the practice that are known to exist by all children with special health care needs in the medical home primary care practice (EIF-eligible patients). A central repository of computerized EIFs would facilitate the identification of all the EIFs in the practice. Improvements in this percentage demonstrate quality improvement.

-EIF maintenance can be monitored by the mean number of days since the last EIF update or confirmation for all the EIFs in the practice. Reducing this mean value demonstrates quality improvement, because more-current EIFs are more accurate.

- The EIF can be used to track the participation level and frequency of disaster drills. Whether this is an actual drill done at home or a discussion or mental review of what to do in the event of a specific type of disaster can be documented in the EIF. Because electrical power failure is such a common event, the EIF should document that an action plan for this has been reviewed with the family and whether an actual trial or drill has been done at home. The percentages of EIFs with a documented electrical power failure action plan review and/or an actual home drill can be used as a quality parameter. Increasing percentages demonstrate quality improvement. As this number approaches 100%, further quality improvement can be documented by monitoring the mean number of days since the last electrical power failure action plan review and/or actual home drill can be used as a quality parameter. Increasing percentages demonstrate quality improvement, because recent review and practice of a disaster action plan should improve the likelihood of success.

**Q U A L I T Y - I M P R O V E M E N T P R O G R A M S U S I N G T H E E I F**

- “EIF maintenance” includes the initial EIF as well as updating it when appropriate and confirming its validity during each health care visit. Each review or modification of the EIF should be dated.

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**E I F C E N T R A L R E P O R T O R Y**

A central repository would provide access by primary care providers, patients, parents, pharmacies, other specialists, and emergency care practitioners.

Although central EIF-repository maintenance and access is highly desirable, implementation faces significant challenges. Measures that promote immediate access and revision/update inherently conflict with measures that preserve confidentiality of protected patient information.

Routine access can be secured by user authentication via the standard method (log in plus password). Known authorized users have access to the EIFs of patients with whom they are known to be linked but not to those of other patients, which permits the expected users of the EIF to have easy access to confirm, update, and revise the EIF at each routine visit.

Emergency access to the EIF is a more difficult issue. The Midwest Emergency Medical Services for Children Information System (www.memsics.org) is an EIF central repository program in Minnesota that uses a “break-the-glass” entry for emergency access to EIF information. This terminology clearly distinguishes routine EIF-maintenance activities from emergency information access. Emergency access via the “glass breaker” is obtained by entering the requestor’s identifying information. No system with broad access can totally guarantee patient confidentiality.

The Internet is far-reaching and is the obvious means to achieve broad access via a centralized server or a linked set of servers. Sophisticated traces can identify unauthorized access sources; however, tracing access from public terminals, unauthorized use of an open terminal, freestanding Internet stations, unsecured wireless networks, and foreign-country access is substantially more difficult or impossible.

Although high security is desired to protect patient information when developing new information systems, it should be noted that standard paper-record systems in use have relatively low security/protection measures. Parents and patients should be made
aware of the inherent compromises in patient confidentiality that must be made to facilitate emergency access. Although perfect confidentiality is often expected or desired, it is unrealistic, especially when compared with the current security status of all health records (paper and electronic).

The Midwest Emergency Medical Services for Children Information System has demonstrated feasibility on a smaller scale, and its experience suggests the need for the advocacy of local physician champions and referral center entities for enrollment success to be achieved.10

THE ROLE OF THE EIF IN PREPARING FOR A DISASTER11,12

● The EIF permits many different health care providers, regardless of background, to provide initial care to children with special health care needs.

● The EIF should include a plan in the event of a disaster, the most common of which is the loss of electrical power. Lack of access to medications, water, food, shelter, and transportation should also be considered. At a minimum, medical home practitioners should consider the planned response for likely emergencies and disasters.

● For technology-dependent children, the loss of electrical power (a common occurrence even in the absence of natural disasters) is a significant disaster event. A simple temporizing measure is that all critical life-support devices should include an internal battery back-up, a power-failure alarm, and a secondary means of back-up power (see Technical Appendix 1). A hospital’s back-up generator electricity is a fairly reliable source of electricity, and transport to the hospital to use it can be considered, but it should not be relied on entirely, because back-up generators are not always reliable, there might be significant traffic getting to the hospital, and there might be overcrowding at the hospital because of other patients doing the same thing. Identifying alternate sites of back-up power should be part of a disaster plan. Hospitals should anticipate their role as a source of electrical power during a prolonged power failure and should plan back-up generator capacity to meet the needs of the hospital plus the needs of technology-dependent patients who are likely to use the hospital’s electrical power.

● The EIF should include a prompt to enter the date of the most recent disaster drill. The most common type of disaster that is anticipated, such as the loss of electrical power.

● The different types, severity, and duration of disasters make it practically impossible to develop a single action plan to specifically and comprehensively manage all disasters. Some geographic regions are more prone to specific types of disasters, and some patients are particularly more vulnerable to specific types of disasters. Determining the most likely disaster (after electrical power failure) is geographic and patient specific.

● Extreme disasters are uncommon, yet survivability during an extreme disaster depends on being prepared in knowing what to do and having the necessary equipment and resources to survive. Extreme and less common disasters are more difficult to drill and are more realistically reviewed with mental exercises that verbally simulate what might happen and what the response would be.

● Because disasters are usually uncommon and difficult to predict, it might be more useful to prepare for generic categories of shortages rather than for a specific type of disaster. For example, several different types of disasters will result in the nonavailability of an important resource that is normally available, such as food, water, shelter, clothing, medication, electrical power, transportation, and medical services. However, mass trauma, bioagent, chemical, or radiation exposure disasters represent challenges that are not necessarily related to resource shortages.

RECOMMENDATIONS

1. Medical home primary care physicians (ideally together with motivated families) are the most qualified persons to globally coordinate completion of the EIF for children with special health care needs13 by obtaining specific recommendations from the pertinent specialists (eg, what type of intravenous fluid to use for a patient with a metabolic condition or what antidysrhythmia measures should be tried first in a patient with recurrent dysrhythmias). Specialty care physicians will need to assist and provide specialty recommendations to ensure that their patients are properly managed.

2. Completion of the EIF should be the responsibility of the medical home primary care physician and specialty care providers for every child with special health care needs. Medical home primary care physicians should be strongly encouraged to include an EIF as part of the patient’s health care maintenance and medical home. For the onset of new conditions for which the tertiary pediatric center has initial access to the patient, an EIF should be initiated during hospitalization (eg, a preterm infant is born, hospitalization...
for newly diagnosed diabetes mellitus, hospitalization for a traumatic brain injury sustained in an automobile collision).

3. Ideally, EIFs should be reviewed periodically by local emergency care providers to confirm that the recommendations are clear and that the necessary specialized equipment, medications, and services are available at the emergency care center.

4. EIF maintenance should be a routine part of the ongoing care of children with special health care needs and should be performed every 6 months (and at each health encounter as needed) to confirm the validity of the EIF and/or update specific changes in the patient’s clinical status on the EIF.

5. End-of-life planning and advance-directive updates and confirmations should be included in the EIF-maintenance process when appropriate. The EIF affords medical home primary care physicians with an opportunity to discuss this most difficult but necessary topic as part of the patient’s ongoing care. This can also serve as a reminder for the medical home primary care physician to discuss with the family the need for any forms required by out-of-hospital providers to honor advance directives.

6. A central standardized electronic repository of EIFs needs to be established and maintained to facilitate updates to and retrieval of EIFs. The repository should be set up by a national medical lead agency, such as the AAP and/or the ACEP, a private national health care organization, and/or an agency of the federal government.

7. An electronic EIF that is compliant with existing American Society for Testing and Materials Continuity of Care Record (ASTM CCR) and Health Level 7 Continuity of Care Document (HL 7 CCD) standards and with HIPAA requirements should be endorsed by the AAP and ACEP as a first step toward a national repository of EIFs. When possible, the EIF data elements should use standardized nomenclature such as the Systematized Nomenclature of Medicine (SNOMED). In addition, the EIF should be accessible via the Internet. EIF standardization will facilitate EHR development and help to ensure that the content of the EIF is accessible in a variety of clinical settings.

8. A central repository does not guarantee availability of the information. A water-resistant paper document or a thumb drive or compact disc that contains the file, kept in a plastic bag (together with insurance papers and other key documents), is more likely to be usable under certain disaster conditions.

9. Quality-improvement parameters of EIF use and maintenance should be added to the growing list of quality indicators for a primary care medical home.

10. Disaster planning should be included as part of the EIF-maintenance process. Medical home primary care providers must consider and anticipate the most likely emergencies and other potentially serious disasters and review the planned response with patients and caregivers. At a minimum, medical home practitioners should consider the planned response for likely emergencies and disasters.

11. Although it might be an expectation that the computerized EIF should be included in this policy statement, the specifications of creating a computerized entity with all the functionality described is a difficult task given the evolution of computer systems, EHRs, access methods, confidentiality/security requirements, and the experience of pilot projects that are currently determining the best way to achieve this. The actual computerized EIF and a reasonable implementation plan should be developed into a technical report to follow. Although other computerized EIF entities have been proposed, it would be premature for the AAP to endorse any of these at this time. A sample computerized EIF is provided for reference (see Appendix 2). The paper EIF version (www.aap.org/advocacy/ EIF.doc) contained in the original policy statement (www.pediatrics.org/cgi/content/full/104/4/e53) can still be manually modified to achieve part of the functionality described above until a computerized EIF standard can be developed and recommended.

12. Fair reimbursement for these services is necessary. Initiating, completing, and maintaining an EIF and other quality-improvement activities associated with the EIF add value but are time-consuming activities that optimize care coordination for children with special health care needs. Optimal care coordination is worthy of and, indeed, contingent on fair reimbursement for these services by medical home primary care and specialty care providers. Current Procedural Terminology (CPT) codes for telephone calls, prolonged service, team conferences, and care-plan oversight and management already exist and can be used to bill for these services. Reimbursement for these services should be a standard part of all health benefit packages.
REFERENCES


and the other rated at 835 W.


TECHNICAL APPENDIX 1: ELECTRIC POWER ALTERNATIVES

A simple and economical recommendation for powering life-support devices in the event of an electrical power failure is for all technology-dependent patients to have an available 12-V inverter, which is an inexpensive device that plugs into a car’s cigarette lighter to deliver 110 to 120 volts of alternating-current (VAC) power. By plugging into a 12-V inverter, the patient’s life-support device can be further sustained by using the automobile’s battery, which can provide power on its own for a moderate period (depending on the power requirements of the life-support device) and indefinitely as long the automobile’s engine is running (until the car runs out of gas). There are different power capacities of 12-V inverters (measured in watts) that must exceed the sum total of the power requirements of the life-support devices required by the patient. For example, if the patient’s ventilator is rated at 110 to 120 VAC, 100 W, and the patient’s oxygen concentrator is rated at 110 to 120 VAC, 150 W, then the 12-V inverters must be able to match this power capacity. This can be accomplished by having two 12-V inverters (one rated at >100 W and the other rated at >150 W) or a single 12-V inverter rated at more than 250 W. Using two 12-V inverters requires that 2 cigarette-lighter sockets be available. Using a single 12-V inverter requires that this inverter have two 120-VAC outlet sockets on the inverter to accommodate both devices.

The power ratings of the 12-V inverters are limited by the electrical current capacity of the automobile’s wiring and fuses. Typically, most cigarette lighters are on 20-ampere (A) (sometimes 10-A) fused lines, which means that if the 12-V inverter draws more than 20 A of current, the fuse will blow (break) and no power will be available until the fuse is replaced. Replacing the fuse with a 30-A fuse (ie, one that is rated higher than what is in the car) is dangerous, because the higher current will exceed the electrical-current capacity of the wiring and could cause a fire. Power in watts is calculated by multiplying voltage and current (amperes). Thus, the 20-A circuit fuse limits the maximum wattage to 240 W (12 V × 20 A). Having 2 cigarette-lighter sockets in the same car does not increase this maximum, because it is likely that both cigarette lighter outlets are on the same circuit. If the sum exceeds 20 A or 240 W, the 20-A fuse will still blow.

The watt rating (power rating) of the life-support device should be stamped on the device itself. If it is not, then the current rating (in amperes or milliamperes) should be stamped. If the device plugs into a standard household outlet, it will be rated at 120 VAC. If the device is rated at 1.5 A, then the power rating will be 180 W (120 V × 1.5 A). The power rating (in watts) of the 12-V inverter must exceed the power rating of the life-support device. These calculations are all theoretical and must be tested in a drill to determine if everything will actually work. During the drill, it should be confirmed that the life-support device is in fact running off of the 12-V inverter and not the device’s internal battery. Depleting the internal battery will test the 12-V inverter’s ability to charge the battery as well, but a back-up power option must be available in case this does not work. Note that it will take more power and current to run the life-support device and charge the battery at the same time, so the drill should test the 12-V inverter under these more stressful conditions. Some devices have uneven power requirements such that periodic surges of power are required. For example, a feeding pump might have a low power consumption while pumping formula, but its power consumption will increase if pumping in something more viscous, such as formula with cereal. Power surges must also be within the range of power that the inverter can deliver.

There are high-wattage (eg, 500, 1000, and 2000 W) 12-V inverters, but they cannot be plugged into an automobile cigarette lighter. They can run off of an automobile battery directly with high-capacity cables. This requires more technical expertise and is more risky, because there is the possibility of a battery short circuit, which could melt wires, damage the life-support device, or cause a fire. If the life-support device requires such high power, it would be useful to get some technical advice on how to do this. The process is similar to “jumping” a dead car battery with jumper cables. A high-wattage life-support device will deplete the automobile’s battery rapidly, so the car’s engine should be running to prevent the battery from dying. The process of starting the car (ie, turning the key) will place a large stress on the car’s battery briefly, which could cause a brief decrease in power to the life-support device if it is running on the car’s battery when the car is started.

Portable generators can also be used to provide electrical power. These generators require gasoline and
motor oil to run. Small generators are rated at approximately 500 W, with larger generators capable of 5000 W and higher. Generators are fairly reliable, but they are often kept in storage and difficult to access when they are suddenly needed. Also, storage does not necessarily guarantee that the generator will work when it is needed. It should be noted that gasoline cannot be stored. Its composition changes with time, and old gasoline will likely damage the generator (similar to putting gum in it) regardless of whether the gasoline is stored in the generator’s tank or in a gasoline-storage container. Because gasoline cannot be easily stored, it is often siphoned from automobile gas tanks. This can be hazardous to the siphoner’s lungs if done incorrectly. Most generators require special motor oil, so several liters of the correct oil need to be available when the generator is run. All of these factors require that periodic drills be done to be certain that the generator will run when it is needed. Follow the generator’s maintenance instructions during periods of nonuse to reduce the likelihood of generator failure when it is truly needed.

The generator or automobile engine must be run in a well-ventilated location to avoid carbon monoxide accumulation. When traveling outside of the United States, it should be noted that different countries use different voltage, current, and outlet-socket configurations.

Sophisticated generators that burn propane, natural gas, liquid petroleum gas, diesel fuel, or fuel oil or use fuel cells are much more expensive and beyond the scope of this report.

Disclaimer: The information contained in Technical Appendix 1 does not represent the opinion, recommendation, or policy of the AAP and is provided for information and consideration only. The AAP recommends that families contact the manufacturer(s) of electrical equipment used in the care of children with special health care needs in developing a plan of action in the event of electrical power failure.

APPENDIX 2: SAMPLE COMPUTERIZED EIF

Disclaimer: The information contained in Appendix 2 does not represent the opinion, recommendation, or policy of the AAP and is provided for information and consideration only as an example of a computerized EIF. It is not intended to serve as a standard of medical care.
## Emergency Information Form For Children With Special Health Care Needs

**Patient ID**
- Patient's name
- Address
- Nickname
- Parents/guardian

**Contact phones**
- Emergency contacts

**Care Provider**
- Provider's name
- Specialties
- All contact phone numbers (E-mail optional)
- Fax

**Facilities & Providers**
- Primary Care
- Specialist 1
- Specialist 2
- Specialist 3
- Specialist 4
- Specialist 5
- Others

**Primary Pharmacy (branch, phone, other)**

**Anticipated primary emergency department (name, phone, other)**

**Anticipated tertiary care center (name, phone, other)**

### Clinical Baseline
- Diagnosis/problem list (list all) starting with most important
- Baseline physical findings
- Baseline vital signs
- Baseline neurologic status
- Immunologic competency status
- Synopsis of clinical status
- Significant lab/imaging/diagnostic studies
- Prosthesis, appliances, advanced technology devices, life support
- Allergies: Medications, foods, substances to be avoided and why
- Advanced directives (include date of last review)

### ED Management
- Suggested studies
- Treatment recommendations

### Immunizations
- DPT dates
- Varicella status
- DTP dates
- Hep B dates
- IPV or OPV dates
- Hep A dates
- MMR dates
- Measles, Mumps, Rubella
- Meningococcal
- Hib dates
- TB status
- Pneumococcal-7
- Hepatitis B
- Other

**Other Immunizations**
- Specify which one if possible

### Disaster Planning & Drills
- Disaster drills reviewed or practiced with patient
- Documentation of completed drills and planned dates for future drills

**Disaster (describe)**
- Other (describe)

**Date**
- Example drills:
  - Verbal review
  - Paper review
  - Table top model
  - Computer simulation
  - Hand on practice
  - Equipment review
  - Home review
  - Alternate electrical power
  - Electric generator

**Describe type of drill**
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