

Considering CSHCN EMS/Trauma Systems RAC Pediatric Outcomes

Prepared for the Pediatrics Committee
Governor's EMS and Trauma Advisory
Council

February 2, 2006

Kathy Griffis-Bailey, MS



Who are we talking about?

American Academy of Pediatrics

Children with special health care needs (CSHCN) are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

Why is it Important?

- 12.6 million children in the U.S. have special health care needs (18% of all children)
- Advances in science and technology have enabled children with complex needs to survive (and thrive!)
 - beyond the neonatal period, AND
 - to live with their families in their own homes
- Acutely ill CSHCN account for 20% of pediatric emergency department visits

Why is it Important?

- Personal preparedness for people with disabilities is on the rise, BUT anxiety levels about personal safety have not decreased in the years since 9/11
- Sixty-three percent of people with disabilities rate the federal government as doing a fair or poor job with emergency preparedness
 - 61% rate state governments as poor or fair
 - 59% rate local governments as poor or fair

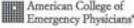
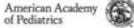
2005 Harris Interactive Survey commissioned by the National Organization on Disability Emergency Preparedness Initiative

Seven critical concerns for families

- Access to care
- Appropriateness of services
- Comprehensiveness of services
- Care coordination
- Continuity of care
- Relation to community
- Family-centeredness of services and system

Ireys, HT et al, *Pediatrics* 98:2, Part 1: 178-85

Emergency Information Form for Children with Special Needs

Emergency Information Form for Children With Special Needs	
 American College of Emergency Physicians*	 American Academy of Pediatrics
<small>Data form completed by Wilson</small>	<small>Revised</small> <small>Revised</small> <small>Initials</small> <small>Initials</small>
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:

Diagnoses/Past Procedures/Physical Exam continued:																																																																																																					
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):																																																																																																				
1. _____																																																																																																					
2. _____																																																																																																					
3. _____																																																																																																					
4. _____	Prostheses/Appliances/Advanced Technology Devices:																																																																																																				
5. _____																																																																																																					
6. _____																																																																																																					
Management Data:																																																																																																					
Allergies: Medications/Foods to be avoided and why:																																																																																																					
1. _____																																																																																																					
2. _____																																																																																																					
3. _____																																																																																																					
Procedures to be avoided and why:																																																																																																					
1. _____																																																																																																					
2. _____																																																																																																					
3. _____																																																																																																					
Immunizations																																																																																																					
<table border="1"> <thead> <tr> <th>Dates</th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> </tr> </thead> <tbody> <tr> <td>DPT</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>OPV</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>MMR</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>HIB</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </tbody> </table>	Dates										DPT										OPV										MMR										HIB										<table border="1"> <thead> <tr> <th>Dates</th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> </tr> </thead> <tbody> <tr> <td>Hep B</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>Varicella</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>TB status</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>Other</td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </tbody> </table>	Dates										Hep B										Varicella										TB status										Other									
Dates																																																																																																					
DPT																																																																																																					
OPV																																																																																																					
MMR																																																																																																					
HIB																																																																																																					
Dates																																																																																																					
Hep B																																																																																																					
Varicella																																																																																																					
TB status																																																																																																					
Other																																																																																																					
Antibiotic prophylaxis:	Indication:	Medication and dose:																																																																																																			
Common Presenting Problems/Findings With Specific Suggested Managements																																																																																																					
Problem	Suggested Diagnostic Studies	Treatment Considerations																																																																																																			
Comments on child, family, or other specific medical issues:																																																																																																					
Physician/Provider Signature:		Print Name:																																																																																																			

Last name:

*Consent for release of this form to health care providers

© American College of Emergency Physicians and American Academy of Pediatrics. Permission to reprint granted with acknowledgment.

Emergency Information Form for Children with Special Needs

www.aap.org/advocacy/emergprep.htm

Endorsed by the American Academy of Pediatrics
and the American College of Emergency Physicians

Emergency Information Form Subject Areas

- Identification of and contact info for child and parent/guardian
- Identification of and contact info for primary care physician and two specialty physicians, pharmacy, anticipated ED, anticipated tertiary care center
- Diagnoses/Past Procedures/Medications
- Physical Exam

Emergency Information Form Subject Areas

- Management data: allergies, meds, or foods to be avoided, procedures to be avoided
- Immunizations History
- Common Presenting Problems/Findings and Suggested Management
- Other Comments

Emergency Information Form Recommended Use

- Prepare Form IN ADVANCE of need
- Prepare Form IN COLLABORATION WITH primary physician (may be a specialist)
- Have MULTIPLE COPIES for home, school, etc.
- UPDATE Form at least annually or as needed
- Use Form in the context of a complete family plan that anticipates emergencies; may include drills, contact numbers, “go bags,” etc.

Recommendation

ADD CSHCN to the Pediatric RAC Objectives and Measurable Outcomes Survey Tool

- Item 5: Recommend resources for RAC members regarding pediatric issues, **including issues for CSHCN.**
- Item 7: Establish performance improvement standards for the care of children in the pre-hospital and hospital settings, **including consideration of children who may be technologically dependent or who may have other special health care needs.**
- New Item: Identify and implement methods to promote and reinforce universal recognition, access to, preparation for, and use of the Emergency Information Form by parents and providers.

Activities/Best Practices In Support of Standards

1. Consider and include CSHCN and adults with disabilities and their families in all phases of community or organization emergency planning and preparedness.
2. Train and practice for the emergency care of CSHCN.

Activities/Best Practices In Support of Standards

3. Promote use of the Emergency Information Form for CSHCN
 - provide blank forms to parents of CSHCN at health fairs, non-emergency health care visits, following an emergency care visit, and/or at hospital discharge
 - promote use of the form by all providers involved in the care of CSHCN
 - work with schools to promote and require completed forms at Admission, Review, and Dismissal (ARD) meetings.

Activities/Best Practices In Support of Standards

4. EMS providers identify and visit medically complicated children prior to an emergency.
5. Listen to the parents/caregivers. They know more about their children than anyone else.
6. Offer to conduct basic life support (BLS) courses at schools or for local clinic staff. They may be the first to identify an emergency.

Activities/Best Practices In Support of Standards

7. Offer to assist others with development of emergency policies and procedures. Provide resources for pediatric emergency information.
8. Remember that families often have ties to particular medical institutions. Taking a child to the wrong destination can lead to adverse effects or death.

Activities/Best Practices In Support of Standards

9. Offer to help create “Go Bags” of emergency supplies and equipment.
10. Include homes, schools, or clinics in drills. Involve law enforcement and other first responders.
11. Include ideas for CSHCN in injury prevention plans and programs.

Activities/Best Practices In Support of Standards

12. Don't let anxiety about a child's special needs cloud the routine. Remember the basics and first assess for ABCs as with any other child.

Considering CSHCN EMS/Trauma Systems RAC Pediatric Outcomes

Kathy Griffis-Bailey, MS
CSHCN Services Program
Purchased Health Services Unit MC1938
Department of State Health Services

1100 West 49th Street
Austin, TX 78756

512-458-7111 x 3069

kathy.griffisbailey@dshs.state.tx.us