

Update on Children with Special Healthcare Needs and Disaster Preparedness

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#DisasterLearning

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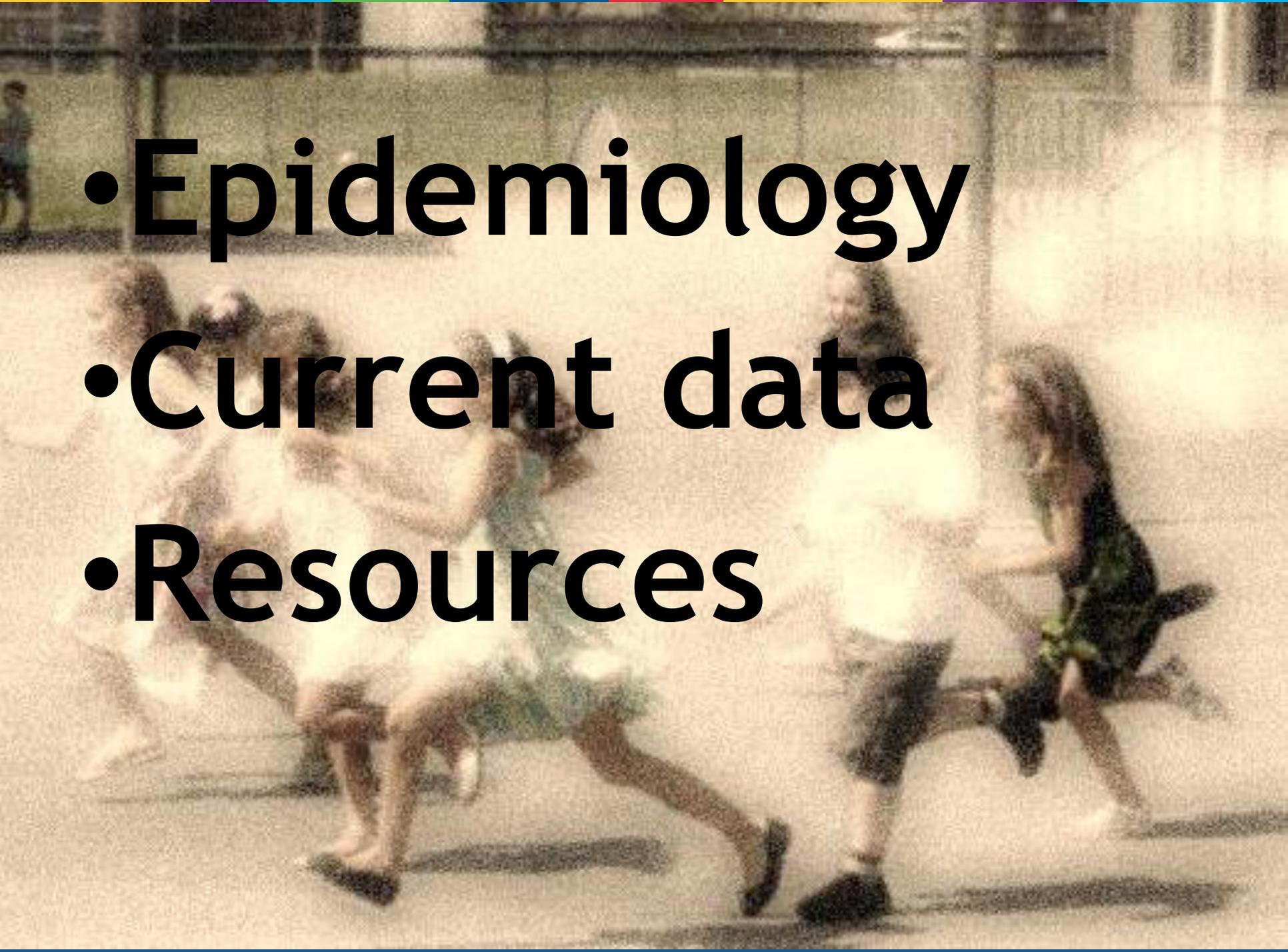
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- 
- **Epidemiology**
 - **Current data**
 - **Resources**



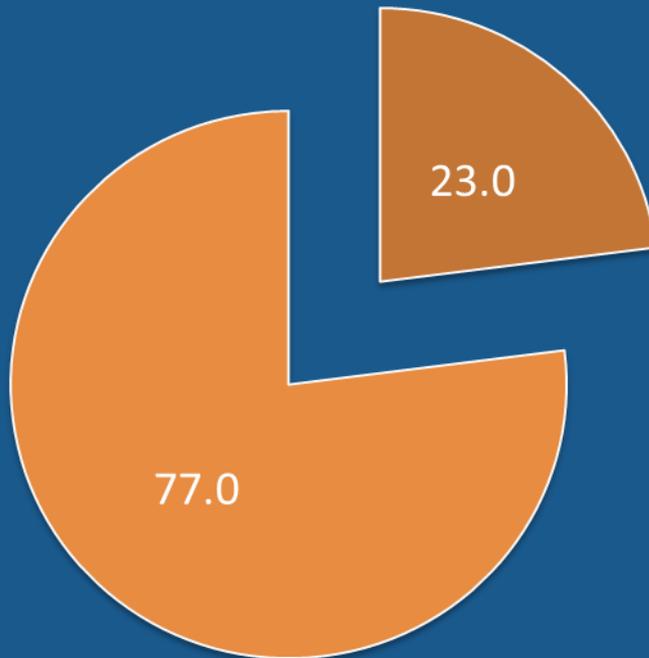
DEFINITION

- “...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.”

McPherson et al., *Pediatrics*, 1998

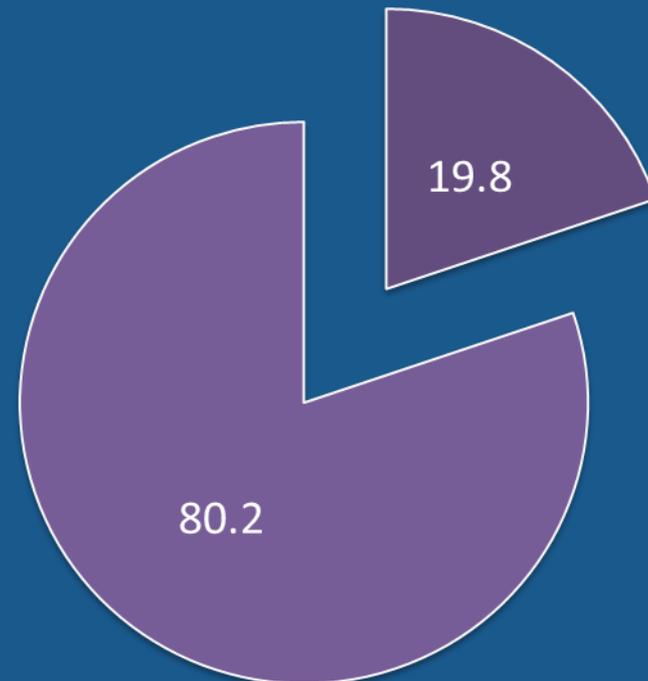
Prevalence Profile

Source: 2009-10 NS-CSHCN



Households with Children

Source: 2011-12 NSCH



Children 0-17 years

Health Issue	% Among CSHCN	Health Issue	% Among CSHCN
ADD/ADHD	32	Bone, joint, muscle	8
Asthma	30	Intellectual	5
Learning disability	27	Hearing	4
Speech problem	16	Brain injury	1
Developmental delay	15	Cerebral palsy	1
Behavioral	14	Tourette Syndrome	0.2
Anxiety	13	Epilepsy	3
Autism spectrum	8	Diabetes	1

Functional Difficulty	% CSHCNs
Learning, understanding, or paying attention	51
Breathing or other respiratory problem	47
Feeling anxious or depressed	43
Behavior problems	41
Speaking, communicating or being understood	33
Making and keeping friends	32
Repeated or chronic physical pain	29
Taking care of self	20
Coordination	20
Swallowing, digesting food, or metabolism	19
Using his/her hands	16
Seeing even with glasses/contacts	16
Hearing even with hearing aid	6
Blood circulation	6



Disaster Preparedness for CSHCNs

Challenges in a Disaster

- Inability to easily or quickly move from an evacuation site to a safe zone without assistance
- Inability to follow directions during an emergency and communicate effectively without assistance
- Diminished availability of medication, medical, and other equipment/technology that depend on for health, communication, and mobility needs

TABLE 1. Level of Basic Preparedness (N=145)

Basic Prep Indicator	Study	APHA	NCDP	CCPR
Emergency supply kit	19.6	21	31	36
Family emergency communication plan	9	17	43	63
3-day supply of water	11.2	-	-	-
3-day supply of food	52.4	-	-	-
Copy of child's medical emergency plan	24.1	-	-	-

Baker et al., *Disaster Med Public Health Preparedness*, 2010

**TABLE 1. Completion and Reasons for Non-Completion of Preparedness activities
(N=238)**

Task	Completed	Do not feel the need to do it now	Would like to but am unsure how	Know what I need to but cannot complete task	Have done it in past but have not updated
Written family emergency plan	12%	6%	51%	19%	8%
Meeting place outside of neighborhood	24%	11%	38%	17%	6%
Copy of medical emergency plan	27%	9%	37%	16%	4%

Baker et al, *Soc Work Health Care*, 2012

Clinical Research

**Mixed-Methods Pilot Study: Disaster Preparedness
of Families With Children Followed in an Intestinal
Rehabilitation Clinic**

Nutrition in Clinical Practice
Volume XX Number X
Month 201X 1–9
© 2015 American Society
for Parenteral and Enteral Nutrition
DOI: 10.1177/0884533615605828
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online.sagepub.com



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and Russell J. Merritt, MD, PhD^{2,3}**

Table 2. General Preparedness Characteristics of Disaster Survey Participants (n=14)

Question	N (%)
Family has a written emergency communication plan in case you are separated during a disaster	
Yes	0
No	14 (100)
Family has 3 gallons of water stored for each person in the household	
Yes	5 (36)
No	9 (64)
Family has enough stored food that does not need refrigeration to sustain their family for 3 days	
Yes	6 (43)
No	8 (57)

Parent Confidence in Family's Preparedness

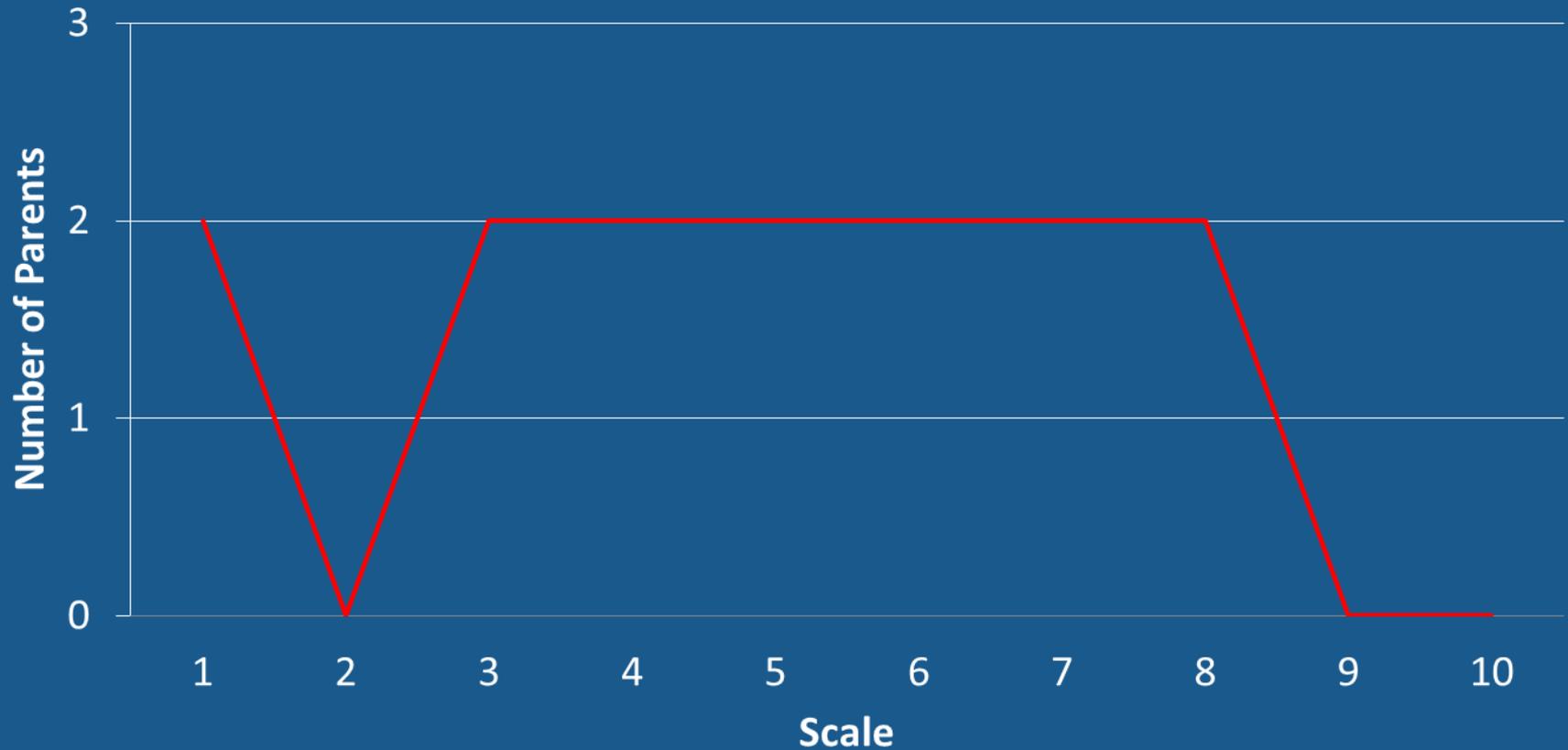


Table 3. IR Disaster Preparedness Characteristics of Survey participants (n=14)

Question	N (%)
All family members over 14 know how to turn off the gas, power and water to our household in case of emergency	
Yes	5 (36)
No	8 (57)
I have a copy of my child's medical emergency plan completed by his or her doctor	
Yes	1 (7)
No	13 (93)
Have a backup source of electricity for their child's infusion pump	
Yes	10 (71)
No	4 (29)



Focus Group Themes

- Supplies
- Medical agencies
- Physicians



Extra Supplies

“I didn’t have any extra tubing. I didn’t have any extra anything. And all I needed to do is always have a bag of fluids with me and then always have tubing with me. I didn’t think about that though. I just figured I’d be able to go home.”



Interacting with Medical Agencies

'And the funny thing is I did ask my pharmacy what, what would happen in a situation like that? They're like, "Uh. We don't know." We're like, "That sounds like the companies aren't prepared for that, either.'



Assistance from MDs

‘So, we get a lot of concerns about like when we come in, we are prepared. And they do have some information out. We try and talk to our doctors about these situations. And they say, “Oh, well that’s just an over, overexcited parent.” And they’ll brush that off. So having something, like you said, from an official letter like that would be very helpful.’



School Disaster Drill

- Preparation
 - School alarm included flashing lights to indicate evacuation
- Response
 - In person communication was direct and clear - as ASL requires eye contact
 - EVERYONE helped set up tents, etc -even those with g-tubes or other medical equipment
 - Police who signed were on hand to communicate with upset parents
- Recovery
 - Demobilization of tents and supplies was quick -everything went back in the bins and brought back to the command post

CHSNCs Considerations

- Evacuation
- Communication
- Supplies



Resources

Disaster Olympix



Disaster Olympix: A Unique Nursing Emergency Preparedness Exercise

Catherine J. Goodhue, MN, RN, CPNP

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Santiago Chambers

Rizaldy R. Ferrer, PhD

Jeffrey S. Upperman, MD, FACS, FAAP

■ INTRODUCTION

The worldwide incidence of natural disasters has increased significantly over the past decade. Since 9/11, emergency planners, public health officials, hospital administrators, and average citizens have shown heightened interest in disaster preparedness and response facilities. Despite the increase in disaster preparedness training and funding, the recent Hurricane Katrina indicates that healthcare organizations remain ill-prepared.² In addition, recent

■ ABSTRACT

Selected Comments from Disaster Olympix Participants

- *Preparation and organization is critical and practice is necessary....response is not intuitive*
- *Working with others and thinking outside of my comfort zone*
- *Great creative areas and loved physically moving and acting out the scenarios*

Pediatric Surge Plan



Project Deliverables

1. Los Angeles County Hospital System Plan for CSHCN
 - Annex to the Pediatric Surge Plan
 - Specific focus on CSHCN and utilizes existing hospital resources within the county

2. Develop web-based platform
 - Provide families with special healthcare needs via two functions:
 - (1) A resource sharing site
 - (2) Opportunity to complete an online emergency information form

Emergency Preparedness

For Children
with Access and
Functional Needs



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EMERGENCY MEDICAL
SERVICES AGENCY
LOS ANGELES COUNTY

Quick Emergency Preparedness Guide

Children with Access and Functional Needs

Be Informed - Be aware about possible disasters in your area. Know what resources are available in your community and what additional resources you might need. Engage your healthcare providers, local Red Cross, and local community partners in the discussion.

Make a Plan - Disasters disrupt daily routines. Create an emergency plan for your family. Include plans for communication, evacuation, sheltering, transportation, and reunification.

Build a Kit - Make sure you have at least a 3 day supply of basic necessities, emergency medical supplies and important documents. Keep copies of your child's medical records, emergency contact forms, and care plan.

Practice and Maintain - Review and practice your emergency plan every 6 months. Routinely check supplies in your kit and replace as needed.

Emergency Supplies

Items to Consider for Children with Access and Functional Needs

Note: *At least a 3 day supply for food, water, formula, and medical supplies*

- Prescription medications, formulas, and medical devices
- First aid kit
- Batteries, generator, flashlight, and can opener
- Battery chargers
- Copies of important documents (*medical prescriptions, insurance policy*)
- Extra medical supplies you regularly use
- A manually operated medical device/mobility aid
- Electronic copies of important documents on a portable USB drive
- Comfort items (*stuffed animal, toys, games*)
- Personal hygiene kit and extra clothes
- 1 gallon of water per person per day
- Non-perishable food items

Preparing for Possible Power Outage

- **Purchase** backup power sources such as batteries, generator, or car power inverter.
- **Purchase** ice packs and coolers if any medication or formulas need refrigeration.
- **Talk** to your power company beforehand. Some companies keep a list and map of power-dependent customers. Also ask what alternative resources they can provide.

Power Outage Considerations – Questions To Ask

1. How long can your child maintain their health without the device?
2. How long can your child's device last without power?
3. What are alternative power sources for your child's device?
4. How long can your child's device run on an alternative power source?
5. Are there alternative methods to the device?
6. Does your child's prescriptions require refrigeration?

Evacuation for Special Needs Population

DAY 1	DAY 2	DAY 3
Identify literature	Evaluate literature	Draft guidance

2014

California Governor's Office of
Emergency Services -- Access and
Functional Needs Evacuation and
Transportation Guidance and Toolkit
Supplement

*Prepared by:
The Center for Collaborative Policy,
California State University, Sacramento*

***DRAFT Version:
December 8, 2014***

Evacuation
Chairs

Registries

Recommendations

Off-site
Locations

Communication

LOS ANGELES COUNTY EMERGENCY OPERATIONS CENTER





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The cover of a brochure titled "Protecting Children During a Disaster". It features a central photograph of a young girl with dark hair in pigtails, smiling. The photo is overlaid with a grid of colorful squares (red, green, blue, yellow). To the right of the photo is a light gray rectangular box containing the text "Place Logos Here". Below the photo and box, the title "Protecting Children During a Disaster" is written in a large, bold, dark blue font. The entire cover is set against a light blue background with a decorative border of colorful squares on the right side.

Place
Logos
Here

Protecting Children During a Disaster



Part 1 - Information

Children with Specific Needs

Facilities serving children with specific needs must invest more time and resources in preparing for emergencies. This will include attention to specific details, such as how to provide specialized equipment (oxygen, special food), appropriate medication and a back-up list of medical providers for each child. Specific locations should be noted for evacuation for the child who needs specific care. Can they manage the route? Do they need protection from the weather?

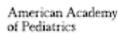
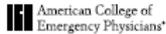
Will anyone in your facility (staff or children) require extra attention during an emergency drill, evacuation or lock down? Indicate their names here and which staff members will be assigned to assist.

Name	Assigned Staff Member

There may be other arrangements you can make now, in advance of the next emergency.

- Plan for a backup power source for medical equipment.
- Plan for the transportation of medications that must be refrigerated.
- Check wheelchair access at your identified evacuation locations (both your close by and far away evacuation sites).

Emergency Information Form for Children With Special Needs



Date form completed 1/1/97 By Whom J. Heav, MD
 Revised 5/15/98 Initials JH
 Revised Initials

Name: Blue, Little B. **Birth date:** 7/4/96 **Nickname:** LB
Home Address: 1313 Mockingbird Lane, Anytown, USA, 11111 **Home/Work Phone:** 900-555-1212 (home) 777-8899 (work)
Parent/Guardian: Sandra Blue, mother **Emergency Contact Names & Relationship:** Beatrice Blue,
 grandmother
Signature/Consent*: *Sandra Blue*
Primary Language: English **Phone Number(s):** 900-444-5544

Physicians:
Primary care physician: Marcus Welby, MD **Emergency Phone:** 1-800-KIDS-KIDS
Fax: 000-000-0000
Current Specialty physician: P. Cavd. Jime Heav, MD **Emergency Phone:** 000-000-0000
Specialty: **Fax:** 000-000-0000
Current Specialty physician: P. Neuro. Joe Newo, MD **Emergency Phone:** 000-000-0000
Specialty: **Fax:** 000-000-0000

Anticipated Primary ED: Smallville Hospital **Pharmacy:**
Anticipated Tertiary Care Center: Childrens All Star Regional Med Center

Diagnoses/Past Procedures/Physical Exam:

1. Tetralogy of Fallot with pulmonary atresia; RV to PA conduit 2/97 VSD left ductus and collaterals ligated
Baseline physical findings: gr III harsh murmur, few crackles at base of left lung, liver down 5 cm

2. Asplenia syndrome

3. thrombosed bilat femoral, iliac veins and inferior vena cava
Baseline vital signs: P 90 BP 100/50 R 24, O₂ Sat 85%
Weight: 12 kg **Dates:** 5/15/98

4. Seizure disorder: generalized tonic-clonic
Synopsis: Asymptomatic, mildly symptomatic w/ Asplenia syndrome noted. Surgery of RV to PA conduit at 8 mos. of age. Post-op seizures-w/RA R. CVA, hemiparesis resolved.
Baseline neurological status: Awake, age appropriate, interactive, mild increased tone L/R. EEG 5/97: mild asymmetry with right-sided slowing

*Consent for release of this form to health care providers

Last Name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:
 1. Digoxin 50 mcg/1cc BID
 2. Lasix 10 mg BID
 3. Amoxil 200 mg BID
 4. Phenobarb 40 mg BID
 5.
 6.

Significant baseline ancillary findings (lab, x-ray, ECG):
 moderate cardiomegaly on cxr
 chronic LLL atelectasis on cxr
 RVH on EKG
 Prostheses/Appliances/Advanced Technology Devices: homograft conduit RV to PA -- no extra precautions. Sternum wires and clips on vessels -- no MRI until 6 mos post-op

Management Data:

Allergies: Medications/Foods to be avoided and why:

1. Betadine rash
 2.
 3.

Procedures to be avoided and why:

1. femoral venous puncture no fem veins
 2. instillation of air into venous catheters R to L intracardiac shunt
 3.

Immunizations

Dates	9/4/96	11/4/96	1/4/97	1/10/98		Dates	9/4/96	11/4/96	1/4/97	1/10/98	
DPT	X	X	X	X		Hep B		X			
OPV	X	X	X	X		Varicella					
MMR				X		TB status					
HIB	X	X	X			Other					Pneumovax

Antibiotic prophylaxis: Indication: Asplenia SBE Prophylaxis Medication and dose: Amoxil 200 mg BID Amoxil 50 mg/kg one hour prior to procedure

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations
Worsened CHF	cxr	increase lasix
Status Epilepticus	check electrolytes/Na check phenobarbital level	midazolam, correct lytes
Fever	sepsis w/u	broad spectrum abx for asplenic individual

Comments on child, family, or other specific medical issues: Mother is an excellent caregiver and knows when LB is blue.

Physician/Provider Signature: *Jime Heav MD* **Print Name:** Jime Heav, MD

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Last Name:

Resources

- AAP
 - <https://medicalhomeinfo.aap.org/Pages/default.aspx>
- Cal OES
 - <http://www.caloes.ca.gov/for-individuals-families/access-functional-needs>
- CDC
 - <http://www.cdc.gov/childrenindisasters/index.html>
- EMSC
 - <http://www.emsresources.org/pedprepared/>
- FEMA
 - <https://www.ready.gov/individuals-access-functional-needs>
- Red Cross
 - <http://www.redcross.org/prepare/location/home-family/disabilities>



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THANK YOU

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