



[www.aboutspecialkids.org](http://www.aboutspecialkids.org)



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ASK E-Newsletter | September 2014



### 2014 Trainings

**Roadmap to Special Education: Laws and Process**  
Sept. 17<sup>th</sup> - Wabash  
Nov. 7<sup>th</sup> – Evansville

**Public Health Insurance: What you Don't Know Can Cost You**  
Sept. 24<sup>th</sup> – Shelbyville  
Oct. 7<sup>th</sup> – Indianapolis  
Oct. 9<sup>th</sup> – Anderson  
Nov. 6<sup>th</sup> – Evansville

**It's Not WHAT You Say . . . It's HOW You Say It: Effective Communication**  
Oct. 13<sup>th</sup> – Columbus  
Oct. 16<sup>th</sup> – Schererville

**My Child Has Special Needs: Now What?**  
Oct. 1<sup>st</sup> – Gary  
Oct. 13<sup>th</sup> – Columbus  
Nov. 6<sup>th</sup> – Indianapolis (SPANISH)

To view the calendar or register for a training, visit our website at [www.aboutspecialkids.org](http://www.aboutspecialkids.org).



### Disaster Preparedness – Let's Talk About It!

by Holly Paauwe, parent and ASK staff Parent Liaison

“Disaster preparedness” – two words that few of us enjoy thinking about, yet they hold such importance for all of us, especially those who are raising children with special needs. Ask almost any parent of a child with special needs what their biggest worries or fears are, and you'll quickly discover that a number of them are shared among us. We fear what will happen to our child when we are no longer able to advocate or care for them. We fear for their health and safety when not in our presence. We wonder how affectively we will be able to respond in an emergency situation, be it medical, man-made, or a natural disaster, to protect our child's health and well-being. We worry about how they will navigate the world as adults and how the world will treat them and protect them in return. These are persistent worries for so many of us. They are the very things that can keep us up late at night and create a sort of chronic anxiety that is ever present in our daily lives. The gift of emergency preparedness is that it provides a means to address and lessen the severity of so many of our fears, but it only works if we actually take steps to appropriately prepare for future emergency or crisis scenarios we may face as a family.

As a parent of a child with complex developmental and medical needs and a parent-to-parent advocate, I don't think we talk about preparedness nearly enough. For our children's sake, we must spend more time talking about what it means and takes to be prepared. We need to recognize and accept the profound responsibility we have as parents to lessen the risk profile for our children and plan for the possible emergency situations our child or family unit could face at any time. Most importantly, we have to act and start preparing. As we do the work necessary to become better and more fully prepared for emergencies and life-changing events our families could face at any time, I suspect we will gain back some of our power and the “peace of mind” that just might be missing from our lives. With that perspective in mind, I hope we can begin to really embrace and appreciate the importance of preparedness to our lives.

If you already have emergency plans in place for your family, then give yourself a pat on the back for having the wherewithal to tackle the task. For those of us without a real emergency plan, or one that is lackluster at best, let's take a moment to think about whether we often find ourselves feeling worried and anxious much of the time. If so, let's challenge each other to change that dynamic. Let's be bold and brave and pick an area of preparedness to start with - right here, right now. It can be

## InSource Positions in South Bend

InSource has two positions available in South Bend – go to <http://insource.org/files/pages/0001-Job%20Openings%20Package.pdf> for more information.



### **ASK welcomes Autumn Coffey**

Autumn joined the ASK team in August 2014 and covers the Southwest region. She lives in Evansville with her husband and two children and stepson. Her son was diagnosed with a rare genetic disorder, Wolf-Hirschhorn Syndrome a week after he was born. She quickly became familiar with navigating the ins and outs of insurance companies, Medicaid waivers, and the early childhood special education system. She has become a strong advocate for her son's needs by educating herself through the internet and countless books relating to numerous topics. Autumn has a degree in Early Childhood Education but became a stay at home mom to care for her son when he was born in 2011. Now that he has started preschool, she is excited to return to the workforce. She is passionate about being able to help families find the resources and supports that will be beneficial to each individual family.



## **Contact Us**

### **About Special Kids (ASK)**

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any area you want it to be, but maybe the one that causes you the most anxiety and stress is good place to start. Let's don't stop there, though. Let's keep looking to each other, and start looking to the professionals that work with our families, for the support and accountability we lack in fully tackling such a complex, difficult and often emotionally heavy task. It's simply too important to ignore and our children certainly deserve our best efforts as we work to develop informed and appropriate emergency plans and procedures for our family. Join me. Act now. Let's do this together.

Because preparing for emergencies can seem like an overwhelming task for some, ASK staff has developed a starter list of suggestions, tips and resources that may be useful in putting together a formal emergency plan that will be more protective of your child and family.

## **Things to Consider**

**Call your fire department's non-emergency number to register your home with 911 as a household with an individual with disabilities that may require specialized assistance.**

- > This is called a "hazard flag"
- > The only one who will see the flag are the dispatcher and first responder
- > First responders will be prepared to assist with your child's particular needs (non-verbal, wheelchair, etc.)

**Build your family's [emergency kit](#)**

**Keep a 1-month medical supply in your emergency kit.** Families can check to see whether their insurance will cover this stockpile of supplies. Medical supplies and medications should be rotated so that they are always current. Plan for an alternate way to keep the medications cold if they usually are refrigerated.

**Plan & prepare as much as possible. Emergency shelters are intended to provide the basics, such as food, water & shelter. Beyond that, you will need to plan how to provide for your family's personal needs.** Think about what supplies, medicines, assistive devices & emergency/health documents you will need.

**Consider using identifying tools for your child,** especially if s/he is non-verbal or has developmental delays. Some ideas:

- > a medical ID bracelet or necklace,
- > personalized clothing tags (for shoes, shirts, etc)

This link has helpful information about **specialized car seats:**  
<http://criss-ca.org/KEEPIN~2.pdf>

**Does your child's IEP have a plan for school evacuations & emergencies?** If your child needs special accommodations during these situations, the school needs to know and be prepared as well. Notify the school that a safety plan needs to be implemented for your child, and work with them to make a plan during your next Case Conference meeting.

**Keep a document with your child's daily needs and medical history in print and electronic formats.** This document should include:

- A detailed daily plan of care;
- Instructions on how to use any medical equipment;
- Allergy information: food/medication allergies, type of reaction, and what to do if the child has a reaction;
- History of surgeries;



### WHAT IS TOPSOCCER? The Outreach Program for Soccer

TOPSOCCER is a community-based training and team placement program for athletes with disabilities, organized by youth soccer association volunteers. The program is designed to bring the opportunity of learning and playing soccer to any players, age 8 and older, who have a mental or physical disability. Our goal is to enable the thousands of young athletes with disabilities to become valued and successful members of the [Indiana Soccer](#) & [US Youth Soccer](#) families. Indiana Soccer partners with [Special Olympics Indiana](#) to make TOPSOCCER Indiana the best it can be.

TOPSOCCER was formed to perpetuate the Indiana Soccer & US Youth Soccer mission statement, which is, in part, "to foster the physical, mental and emotional growth and development of America's youth through the sport of soccer at all levels of age and competition." There are thousands of children with disabilities who need, and can be provided with, the opportunity to play soccer through the TOPSOCCER program.

Go to <http://www.soccerindiana.org/programs/topsoccer.aspx> to find a program in your area and to register your child.

If you have questions about this program, contact [Joy Carter](#), TOPSOCCER Staff Liaison for Indiana Soccer



- Diagnoses by body systems; include a body map if applicable
- List of doctors, pharmacists, and equipment providers and their contact information;
- Medications and supplies with stock numbers and basic descriptions of products for comparable substitutions in case the exact product isn't available;
- Insurance information and/or a caseworker for the child's Medicaid waiver and related information;
- Special items such as a recipe for formula, catheterization schedule, or legal documentation; and
- A biographical sketch: the child's likes and dislikes, hobbies and interests, and triggers, or things that might disturb him or her

Contact your [county's emergency management office](#). Many local emergency management offices maintain registers of people with disabilities so they can be located and assisted quickly in a disaster.

### Indiana Department of Homeland Security

Indiana Government Center South  
302 W. Washington St., Room E208  
Indianapolis, Indiana 46204  
(317) 232-3986  
<http://www.in.gov/dhs/index.htm>

### Online Resources:

To check out information from Riley's Safe Escape website go to - <http://safescape.rileychildrenshospital.com/>

For you own needs assessment and emergency evacuation plan go to [http://safescape.rileychildrenshospital.com/pdf/EN/evacuation\\_plan.pdf](http://safescape.rileychildrenshospital.com/pdf/EN/evacuation_plan.pdf)

Medical Alert information: <http://medipal.com/> OR <http://www.americanmedical-id.com/category/medical-ID-bracelets-for-kids-17>



REMINDER: About Special Kids has been nominated by a friend at Century 21 Scheetz for a chance to win a \$5,000 grant from Realtor Foundation.

Please go to the Realtor Foundation Facebook page NOW and like them – and vote for ASK until 9/14. Top vote getters go to final round where you can vote again, the charity with the most votes wins the \$5,000 grant.

Vote NOW at [www.facebook.com/realtorfoundation](http://www.facebook.com/realtorfoundation)

We want to thank ASK's good friend,  
Shereen Wallace, Branch Leader

