

AMERICAN ACADEMY OF PEDIATRICS AND FAMILY VOICES
Summary of June 2015 Pilot-test of Educational Handouts
Starting the Preparedness Conversation with Pediatricians and Families

Partnership and Project Details

The American Academy of Pediatrics (AAP) partnered with Family Voices in 2015 to develop and pilot-test draft educational handouts for pediatricians and families in regards to improving preparedness for children and youth with special health care needs (CYSHCN).

The Pilot-test Process

The AAP and Family Voices worked together to develop survey and focus group questions. There were three basic sets of questions: one for family members (21 questions), one for family leaders (23 questions), and another for pediatricians (17 questions). Basic demographic questions were asked as well as specific questions on the content of the existing handouts and ideas for encouraging increased communication between a pediatrician and a parent or family. These sets of questions were adapted into eight unique surveys for pediatricians, family leaders, families in five individual states, and one generic state survey. In addition, two focus groups were held, using questions from the surveys to elicit more in-depth conversations on preparedness and CYSHCN. Once feedback was received and reviewed, a conference call was held with pediatricians and select family leaders to discuss challenges and strategies related to pediatrician and family conversations about improving preparedness for CYSHCN.

Respondent Demographics

Survey Responses

In total, survey responses were received from 120 individuals across the three groups (Families, Family Leaders, and Pediatricians), representing diverse family/family leader input from at least 9 states and pediatricians from at least 8 states. Respondents came from geographic areas prone to a variety of natural disasters, including hurricanes, tornados, and floods, and many of the respondents have lived through one or more of these disasters.

Many of the questions asked for comments, often in addition to checklist items. In total, there were 470 comments received. Select participants mentioned that reviewing the materials and participating in the call inspired them to take additional action right away.

Focus Groups

The two focus groups included a Kansas group of 7 family representatives—parents with CYSHCN (and one young adult with a disability); and a New Jersey group of 10 Family Resource Specialists/Parent Leaders, all parents of CYSHCN. The disabilities represented in these two groups included autism, emotional/intellectual/developmental delays, orthopedic impairment, deafness, visual impairment, and language deficits. The Family Leader group included representatives from many ethnic backgrounds and immigrant communities.

The demographics and response numbers of respondents to the surveys and participants in the focus groups are summarized in the chart that follows:

TABLE ONE: SUMMARY OF DEMOGRAPHICS AND RESPONSE NUMBERS									
	No.	Asian	Black	AIAN	Pacific Islander	White	Other	Hispanic	Number of Comments
SURVEY									
Families	56	2	6	2		43	4	9	177
Family Leaders	41	2	7	1		22	9	14	219
Pediatricians	23		1			21	1	1	83
Total	120	4	14	3		66	14	24	470
FOCUS GROUP									
Families (KS)	7					4		3	
Family Leaders (NJ)	10		1				6	3	
Total	17		1			4	6	6	

Summary – What Results Revealed

Parents of CYSHCN share many of the concerns about emergency preparedness that worry parents of typically developing children. Knowing what to do, where to go, how to make it through days of limited supplies, and how to rebuild after a disaster occurs are important—and stressful—topics for all families. Families with CYSHCN, however, face additional concerns preparing and caring for their children’s medical issues during such emergencies.

Participants in the surveys and focus groups reviewed the existing handouts, one for families of CYSHCN and one for pediatricians serving these families. The following themes emerged related to ways to improve communication between the pediatrician and the family.

1. Families’ understanding of what they need to do to prepare for—and recover from—emergencies and disasters vary, as does their ability to cope with new information. This requires sensitivity in how families are approached, and it requires starting where they are.
2. In a disaster-prone area, many families are still struggling to recover from one disaster before the next one hits.
3. Families will likely find these topics unfamiliar and may be overwhelmed with the information. They may need help in deciding how to proceed.
4. The most ideal solutions to ensuring a family with a child with special needs is truly prepared for a disaster are not necessarily feasible for families. These families may lack the resources to handle the suggestions or simply cannot afford them.
5. Stories/examples can be used to reinforce to families why it is so important to prepare for disasters.
6. A lack of time and the need to address other priority topics during office visits makes it challenging for both the pediatrician and the family.
7. Materials need to be translated and culturally appropriate for ethnic groups in a given area. Translation issues are a serious barrier, especially for recent immigrants and adopted children from other countries.

Lessons Learned about Improving Communication between Families and Pediatricians

Pediatricians

- Because families may find these topics unfamiliar and overwhelming, they will likely need help in deciding how to proceed.
- Handouts and resources are helpful tools. The existing pediatrician handout is too long and needs to be condensed and simplified. Checklists might help.
- These conversations with families are difficult—disaster preparedness is a complex topic with many components, and the lack of time and other priorities for office visits make these conversations even more challenging.

Families

- Families look to their pediatricians for support and guidance on this topic.
- The existing handout for families was too long, and needs to be condensed and simplified. It would help to divide the handout into discreet topics or sections that can be addressed one at a time.
- Families with CYSHCN must prepare for disasters with the specific needs of their child in mind. This requires time, knowledge, money, and support. Each family needs to be helped to realize and understand the impact on the child if the family is NOT prepared.
- Many families with CYSHCN already spend much of their time in day-to-day care of their children, and finding time to prepare for an emergency or disaster that may not happen is a lower priority.
- Mental health concerns add an additional layer onto preparation, as well as recovery afterwards.

Recommendations for Next Steps

The AAP and Family Voices will work together to encourage stakeholders to implement the following:

Pediatricians Can:

- Look for ways to incorporate preparedness discussions into office visits.
- Assess where families are in preparedness planning and help them create a plan to get ready.
- Incorporate relevant information into the patient's electronic health record.
- Help families link to resources and assistance from other sources, especially peer support such as the Family-to-Family Health Information Centers in each state.

Families Can:

- Work with the pediatrician to develop a plan that works for the family.
- Begin to take steps towards preparing for emergencies and disasters. Seek out resources and support from other sources, such as the Family-to-Family Health Information Centers in each state.

Organizations/Community Groups Can:

- Include family leaders or members in the review process when developing materials.
- Seek input from pediatricians when developing child health resources or initiatives.

The AAP and Family Voices will also work together to a) create and update Web pages for pediatricians and families based on feedback received during the pilot-testing of the educational handouts, b) produce, post, and circulate revised versions of the handouts for pediatricians and families, c) conduct a webinar or audio call on starting the preparedness conversation with pediatricians and families, and d) investigate new formats to share preparedness material and information (eg, infographics, PowerPoints with voice-overs, and video clips). For more information, e-mail DisasterReady@aap.org.