

Initial Report

Families Know Best - June 2015

Modified: 06/26/2015

Please identify yourself.

#	Answer	%
1	Mother	100%
2	Father	0%
3	Legal Guardian	0%
4	Other (Please Specify)	0%
5	Foster Parent	0%
	Total	100%

What is your child's disability or health condition?

Text Response	%
Autism/ ASD	39
Down Syndrome	13
multiple disabilities, CP, genetic syndrome	4
Type 1 Diabetes	4
Traumatic Brain INjury	4
Rhett Syndrome	4
CP, epilepsy	4
asd,adhd,odd	4
Autism, SPD, Asthma	4
autism, down syndrome, hearing impairment	4
Developmental delay	4
Orthopedic	4
Unilateral polymicrogyria resulting in hemiplegia. Epilepsy. Developmental delay	4
Trisomy 21	4

What is your place of residence?

#	Answer	%
1	New Castle County, DE	71%
2	Kent County, DE	17%
3	Sussex County, DE	4%
4	Other - Pennsylvania Resident	4%
5	Other- New Jersey Resident	4%
6	Other- Maryland Resident	0%
	Total	100%

What is the age of your child?

#	Answer	%
1	0 - 4 years old	8%
2	5 - 11 years old	63%
3	12 - 21 years old	29%
4	Over 21 years old	0%
	Total	100%

What is your race/ethnicity? (Check all that apply)

#	Answer	%
1	White	75%
2	Black, African Am., Negro	13%
3	Asian/ Pacific Islander	8%
4	Hispanic, Latino, or Spanish origin	13%
5	Native American	8%
6	Other (Please Specify)	0%

What are 3 essential things that your child with a disability or chronic health condition would n...

1)	2)	3)
An item to keep him occupied		
water	food	TV
diapers	food	family
medications	incontinence supplies	stairlift
Extra meds if necessary	Adequate food & water	Back up power
Insulin	Blood glucose testing meter	Glucagon
Medicine	Non caffiene drinks	several changes of clothes
Supply of medications	Ability to keep medication refrigerated	
Electricity	Medications	Formula
food	water	shelter(he would say video games)
Asthma medication and nebulizer with power to operate it	specialized medical food (amino acid based formula)/water	communication and comfort tools
access and availability of daily medications	access to potable water and food	ability to maintain a reasonable temperature
Food	Clothes	Water
medications	electric for communication device	special diet foods

Does your child with special health care needs require any of the following items or accommodatio...

#	Answer	%
1	Prescription medication	86%
2	A special diet	33%
3	Diabetic supplies	5%
4	Electrically powered equipment (ventilator, suction machine, electric wheelchair, etc)	19%
6	Accessible transportation	24%
7	A service animal	5%
8	Batteries for a hearing aid or other necessary equipment	10%
9	Assistance with communication	43%
10	A quiet space with low sensory stimulation	52%

Does your family have a general emergency plan for your household in case you would need to stay...

#	Answer	%
1	Yes	59%
2	No	41%
	Total	100%

Do you have an emergency plan that addresses the specific items that your child needs to maintain...

#	Answer	%
1	Yes	50%
2	No	50%
	Total	100%

Does your plan include the following items? (Please check ALL that apply.)

Answer	%
Contacts, including family, and friends with the best way to reach them during an emergency	85%
A list of phone numbers for your doctors, pharmacy, and the medical providers that you use	100%
A list of the medications that your family uses on a daily basis including the prescription numbers and the phone numbers of the pharmacies where you get the medication	85%
Arrangements with your in-home care provider for continued care during an emergency	8%
A back-up plan for electrically powered equipment in case of a power outage	15%
Identification of 2 or 3 people who could help you with some of these concerns during an emergency situation	46%
TV and radio stations that carry emergency updates for your area	46%
A “go-bag” that contains the supplies you would need to remain in your home or evacuate for 2 or 3 days	69%
Numbers of your local police and fire station in case you need to call them for non life-threatening assistance during an emergency	54%

Do you know where to get assistance in developing an emergency plan that addresses the needs of c...

#	Answer	%
1	Yes	45%
3	No	55%
	Total	100%

Have you visited the alreadyde.org website?

#	Answer	%
1	Yes	27%
3	No	14%
5	I was not aware of that resource	59%
	Total	100%

Would you be interested in a text messaging program to help you prepare for an emergency in weekl...

#	Answer	%
4	Yes	14%
5	Maybe	36%
6	No	50%
	Total	100%

Please feel free to share any comments or concerns regarding emergency preparedness.

Text Response

i just havent put much time into this because i have so much else to worry about and get in pace all the time

when your income is limited and further stressed by special health needs/ supplies, it is difficult if not impossible to get "extras" for emergency situations. We are just trying to get by with day to day needs

I'm very short on time to plan for anything. Having a ready to go kit with essentials for the house would be excellent.

With my daughter, my biggest concerns is her inability to understand what & why there is an emergency.

I would be interested in an *e-mail* messaging program to help me prepare for an emergency. (I would prefer one large message over weekly installments, but either would work.)