

Initial Report

Families Know Best - March 2014Last
Modified: 03/26/2014

Does your child have a disability, developmental delay or chronic medical or mental health condition?

#	Answer	%
1	Yes	100%
2	No	0%
	Total	100%

If yes, please share your child's diagnosis with us.

Text Response
diabetes
Multiple disabilities, CP
autism (severe), failure to thrive, G-tube, food allergies
Type 1 Diabetes
Polymicrogyria , epilepsy, hemiplegia
Down syndrome
Static encephalopathy, cp, seizures
down syndrome, autism, hearing impairment, cuteness syndrome!
Autism
Autism
Rett Syndrome
Autism
PDD NOS
Autism
Hydrocephalus; anxiety, TBI- memory loss
Autism

What is your county of residence?

#	Answer	%
1	New Castle County, DE	78%
2	Kent County, DE	13%
3	Sussex County, DE	0%
4	Other - Pennsylvania Resident	4%
5	Other- New Jersey Resident	4%
6	Other- Maryland Resident	0%
	Total	100%

Do you use the Internet when searching for resources for your child's needs, or those of your family?

#	Answer	%
1	Yes	100%
2	No	0%
	Total	100%

Please tell us about any websites that you have visited and found good information regarding your child's health and well-being or education.

Text Response
Children with Diabetes, dlife, parent informations center, Family SHADE, JDRF
Kids Health, WebMD, anywhere Google leads me!
http://www.autism.com/ , http://picofdel.org/ , http://www.delautism.org/ , and http://www.foodallergy.org/ , among many others
JDRF, American Diabetes Association
Hemikids list serve, pmg yahoo group, pmg awareness
Mostly special need blogs
Nemours, epilepsy foundation, various message boards
picofdel.org , family voices, SHADE, de dept of education, wrights law
webmd, autism delaware, autism speaks
Talk About Curing Autism (TACA), Autism Research Institute (ARI), Autism Delaware
rettsyndrome.org ; rifton.com
Autism delaware
imdetermined.org ; wrightslaw.com
Autism speaks, parent information center
NDSC.org
Various national websites depending on the topic I am researching

What information would you most like to see on-line that you havenot been able to find in regard to your child's health and wellness or education?

Text Response
more diabetes info for Delaware
information about undiagnosed children as they get older
How to deal with the changes that will be coming as he hits puberty.
More self help ideas for hemiplegia. Adaptive dressing, recreation, etc
Adapting lessons to special needs
Benefits under Medicaid, adaptations for home
list of mental health providers and board certified behavioral analysts
Assistive Technology speech therapist - those who teach communication apps to kids with autism
PA legal code for educating children with special needs similar to NJ Administrative Code 6A chapter 14
Respite
Medicaid funding ABA, education for autism
how to help him obtain a part time job given his disabilities
Child care for children with a disability
How to work with child
How to help him get part time work
Social, recreational

7. What search terms do you use when browsing for information on resources for your child?

Text Response
diabetes, support, research
pediatric wheelchairs, CP, kyphosis, scoliosis, hippotherapy, pediatric physical therapy, augmentative communication, respite, genetic testing
That depends on precisely what I am searching for. suppose, for example, I wished to find something dealing with some maladaptive behavior -- hitting, for example. I might search using the terms: autism, behavior modification, hitting. I would modify this as appropriate.
Type 1 Diabetes Resources
Polymicrogyria , hemiplegic
Special needs
Delaware, seizure, hypotonia, varies depending on needs
google phrases
education, special behaviors
Biomedical, Allergy, Supplements,
special needs, durable medical equipment, child with disabilities
Autism
special education, suing your school district for dummies,
Autism education, ABA, medical necessity

What, if any, services are you receiving for your child?

Text Response
504 plan, support group, medical care at Nemours
through school - OT, PT, Speech, Vision - and - outpatient PT, orthotics
Covered by Medicaid: occupational therapy and speech therapy, plus medical appointments (gastroenterology, neurology). Partially covered by my insurance: social skills class.
Support from Nurse @ school, visits with her Endocrinologist, and with Nutritionist.
Ot pt st orthotics
None
Therapy thru school, respite
school based services
IEP through school
Delaware Autism Program, OT, PT, ST, and ABA
She gets OT, PT and Speech at school. Additionally she gets PT privately. We have Medical Assistance as a secondary insurer.
Speech, OT, Sensory a Integration, ABA
speech, OT, social skills, RTI: math & reading
PT/OT/speech/spec Ed at school, ABA, speech, OT, music therapy, social skills class
DVR

Have you ever searched for information on any of these topics and NOT been about to find resources? Please choose all that apply.

#	Answer	%
1	Health care	13%
2	Child care	38%
3	Education	31%
4	Recreation	31%
5	Support groups	38%
6	Other (please specify)	31%

Person completing this survey:

#	Answer	%
1	Parent	100%
2	Grandparent	0%
3	Guardian	0%
	Total	100%