

Initial Report

Resources for Healthcare and Policy Information  
Families Know Best - December 2019

# 1 - What is your place of residence?

Answer	Count
New Castle County, DE	15
Kent County, DE	5
Sussex County, DE	3
Other - Pennsylvania Resident	4
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	28

## 2 - Please identify yourself.

Answer	Count
Mother	22
Father	1
Legal Guardian	3
Foster Parent	2
Other (please specify)	0
Total	28

### 3 - What is the age of your child?

Answer	Count
0-4 years old	0
5-11 years old	13
12-21 years old	12
over 21 years old	3
Total	28

#### 4 - What is your child's race/ethnicity? (Check all that apply)

Answer	Count
White	17
Black or African American	6
Hispanic, Latino, or Spanish Origin	3
Asian	3
American Indian or Alaska Native	2
Native Hawaiian or Pacific Islander	0
Other (please specify)	1
Total	32

#### Other (please specify) - Text

Bi-Racial

## 5 - What is your child's disability or health condition?

What is your child's disability or health condition?	Count
Autism	9
Cdk13	1
Down Syndrome	1
Mild intellectual disability	1
Polymicrogyria (brain malformation) causing hemiplegia, epilepsy and developmental delay	1
Rett Syndrome	1
Type 1 Diabetes	1
Continued on next slide =>	

## 6 - What is your child's disability or health condition?

What is your child's disability or health condition?	
Multiple:	10
autism, motor deficits	
Autism, asthma, malabsorption disorder	
Autism with ADHD	
ADHD and anxiety	
PTSD, ADHD, Depression	
Epilepsy and ADHD	
Deaf, CHD (repaired PDA), microcephaly (diagnosed but no apparent effect on development, behavior, etc)	
Moderate Intellectual Disability, Down Syndrome, and autism	
Rare genetic disorder, CP, multiple disabilities	
TBI/ hydrocephalus	
Total	25

7 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

Answer	Count
Yes	19
No (please explain below):	6
Total	25

#### No (please explain below): - Text

doesn't cover physical therapy or supports for physical activity, limited coverage and difficulty getting ABA covered

Primary private insurance does not cover all of my daughter's care or DME needs. Thankfully Medicaid covers whatever her primary does not.

Doesn't cover lot of good places like hypotherapy, music is therapy

Nothing is approved—- medical necessity is needed for pretty much everything. There is such a long delay from the initial need and order to when we can actually get what he needs.

Doesn't cover anything we need, no specialists

Although my son's and my legal residence is in Delaware (and thus he has Delaware Medicaid), his special needs are severe enough that he needs to attend an out-of-state residential school. I wish Delaware's Medicaid were accepted in Pennsylvania.

## 8 - What is your age?

Answer	Count
18 - 25 years old	0
26-35 years old	4
36 - 45 years old	6
46-55 years old	12
55+ years old	3
Total	25

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

Answer	Count
White	19
Black or African American	4
Hispanic, Latino, or Spanish Origin	0
Asian	2
American Indian or Alaska Native	0
Native Hawaiian or Pacific Islander	0
Other (please specify)	0
Total	25

## 10 - What are your biggest challenges around the healthcare needs of your child?

Answer	Count
Medical services	13
Therapies (i.e. physical therapy, occupational therapy, speech pathology, etc.). Please specify.	8
Medications Costs/Access	9
Dental services	3
Medical transportation services	1
Incontinence supplies	4
Other. Please specify.	9
Total	47

Therapies (i.e. physical therapy, occupational therapy, speech pathology, etc.). Please specify.
aba
His father works for AI so we can to see a therapist at AI and we haven't been able to stay with one for a long period so we're constantly changing them
PT oT and speech
She qualifies for services at school but fir additional services we are sometimes limited by insurance in the number of outpatient visits
therapies for autism

## 10 - What are your biggest challenges around the healthcare needs of your child?

### Other. Please specify. - Text

Hearing aid batteries

DME such as wheelchair

appointments

no recent issues

home health aide, respite

Amino acid based formula, autism related DME

Long waits in doctors' offices. Also, health professionals who have the training and the empathy necessary to work with my son.

None

Extra curricular

## 11 - Please elaborate on the challenges you face.

### Please elaborate on the challenges you face.

Finding adult medical providers downstate who understand autism; ABA coverage; support for physical fitness activities because he has motor deficits and exercising with support is needed

Our challenges remains with getting to medical services with my daughter. Her primary caregiver is located in Wilmington and we live in Dover. Medicaid limits prescriptions to 30 days even though some of her medications are maintenance ones.

we have been on a wait list for almost 5 years for ABA services. We are all on several waitlists, meanwhile my son's behavior is out of control and he is destroying everything in our home.

We are fortunate to have secondary Medicaid for our son, so generally all our medical services (audiology, cardiology, etc) are covered. However, it would be helpful to have coverage for things like hearing aid batteries. Also, it was challenging to fit speech therapy into his schedule, so we stopped that.

Not enough doctors qualified to deal with childhood apraxia of speech

knowing what services are available to my child

We also keep changing therapists because the state has downgraded his 'needs'

## 11 - Please elaborate on the challenges you face. (continued)

### Please elaborate on the challenges you face.

Medications - primary is constantly requiring preauthorizations to remain on medications that she has been on for years. They would prefer us to switch to cheaper or generic meds. Also we have had to switch pharmacies numerous times to stay within the changing list of network pharmacies. Recently had to get special approval to continue using a compounding pharmacy for med.

Services - therapies are rarely covered. Copays and deductibles would be impossible to afford if it were it for Medicaid.

DME - have had trouble getting equipment fully covered. For example, private insurance covered frame of wheelchair, it not headrest, side lateral supports, foot plates.

Getting my adult son to independently take care of scheduling his appointments without frequent reminders.

No coverage of nursing or home health aid .

There is such a long delay from the initial need and order to when we can actually get what he needs.

It took TWO weeks to get medication for aggression approved. Meanwhile family members and school staff get injuries and my kid suffers.

Her epilepsy med is now available in a generic so there is pressure from insurance to stop using the brand name which has worked very well for her for since 2 weeks of age- her neurologist has to obtain a special code yearly so we can continue to get brand name and pay our usual copay

## 11 - Please elaborate on the challenges you face. (continued)

### Please elaborate on the challenges you face.

recently we have not had challenges

ABA Analyst therapy - not enough providers

It's difficult to find dentists who specialize in children with needs as complex as my child's, especially when he needs to be sedated for dental work. In addition, we haven't been able to source a home health aide since moving to PA, and when we lived in DE, it was often difficult to find a substitute for afterschool hours. Likewise, it's hard to find suitable care for respite.

The biggest challenge is finding doctors who can help my child that also accept our health insurance.

Amino acid based formula, autism related DME and therapy, rxs not covered or require prior auth and dr never follows thru.

My son's behaviors can be quite challenging; the combination of nervousness and sensory overload combine with the difficulty he has in waiting, and by the time a medical professional actually comes into the examination room, my son is usually quite agitated. This results in a situation in which he can not have as thorough an exam (if, indeed, any exam at all). I would \*love\* to be able to arrange for my son to be seen at the actual time his appointment is, rather than having to wait his turn.

## 11 - Please elaborate on the challenges you face. (continued)

Please elaborate on the challenges you face.

None

I'd like help in figuring out what is available to us with extra curricular activities

the pediatric Doctors cared so much more about my son's health

Cost of medical supplies

12 - What are your sources for healthcare information and resources? (Please check all that apply.)

Answer	Count
National organizations. Please specify.	8
National government agencies. Please specify.	3
Local organizations/agencies. Please specify.	7
State/local government agencies. Please specify.	5
Websites. Please specify.	9
Social Media. Please specify.	5
E-mail list-servs/Newsletters	4
Other. Please specify.	8
Total	49

12 - What are your sources for healthcare information and resources? (Please check all that apply.)

**National organizations. Please specify. - Text**

JDRF

TACA and National Autism Association (NAA)

Health and welfare

Autism Speaks

**National government agencies. Please specify. - Text**

DHSS

Autism Speaks

**Local organizations/agencies. Please specify. - Text**

DSA

Delaware Family Voices, Family SHADE (both while we were in Delaware)

Autism Delaware

Chester county mental health/ intellectual and developmental disabilities dept.

Down Syndrome Association

12 - What are your sources for healthcare information and resources? (Please check all that apply.)

**State/local government agencies. Please specify. - Text**

DDDS/DDC

New Jersey epilepsy foundation

Autism DE, PIC, DDDS

DDDS, Down Syndrome Clinic, Wilmington

**Websites. Please specify. - Text**

Autism Speaks

Insurance agencies' sites listing preferred providers, deductibles, etc.

Autism Research Institute, Autism Treatment Center of America

ADDitude is a great one

Mycigna.com, Medicaid website

**Social Media. Please specify. - Text**

Autism Speaks

Facebook

Facebook groups

Rett Syndrome family Facebook page

12 - What are your sources for healthcare information and resources? (Please check all that apply.)

**Other. Please specify. - Text**

N/a

school social workers, other parents

doctor

I used to be on hemikids list serve but they required a certain number of posts so I left that group

Our case worker

many others and books on fostering independence

None really

Honestly, I'm not sure of all my sources for healthcare information and resources. We get a lot of our information from my son's school (Delaware School for the Deaf), which shares all sorts of information, not just education-related. Also, organizations like yours, as well as national nonprofit organizations and, of course, many websites. I really don't think I could detail which ones, since I pull from dozens of sources, depending on the issue and what I'm looking for.

13 - What are your sources to better understand federal disability/health policy information?  
(Please check all that apply.)

Answer	Count
National organizations. Please specify.	2
National government agencies. Please specify.	2
Local organizations/agencies. Please specify.	5
State/local government agencies. Please specify.	4
Websites. Please specify.	4
Social Media. Please specify.	3
E-mail list-servs/Newsletters	1
Other. Please specify.	10
Total	31

13 - What are your sources to better understand federal disability/health policy information?  
(Please check all that apply.)

**National organizations. Please specify. - Text**

National Autism Association

**National government agencies. Please specify. - Text**

SSA

**Local organizations/agencies. Please specify. - Text**

Parent information center

Dsa

**State/local government agencies. Please specify. - Text**

Autism DE

dhss

13 - What are your sources to better understand federal disability/health policy information?

(Please check all that apply.)

**Websites. Please specify. - Text**

Social security website

Autism Speaks

**Social Media. Please specify. - Text**

Facebook

Facebook groups

13 - What are your sources to better understand federal disability/health policy information?

(Please check all that apply.)

**Other. Please specify. - Text**

I do not have one.

Again, this is similar to my answer above. For example, when dealing with a recent ADA issue with my son's pediatrician, I reached out to my son's school, researched the law online, and contacted our local deaf advocate.

None

Newspaper, online

a few others others

Case worker

Really have not investigated federal information at this age for her

lawyer

I need some!

N/a

14 - What are your sources to better understand state disability/health policy information?  
(Please check all that apply.)

Answer	Count
National organizations. Please specify.	2
National government agencies. Please specify.	2
Local organizations/agencies. Please specify.	5
State/local government agencies. Please specify.	9
Websites. Please specify.	6
Social Media. Please specify.	3
E-mail list-servs/Newsletters	1
Other. Please specify.	7
Total	35

14 - What are your sources to better understand state disability/health policy information?  
(Please check all that apply.)

**National government agencies. Please specify. - Text**

SSA

**Local organizations/agencies. Please specify. - Text**

The ARC of Chester County

Dsa

**State/local government agencies. Please specify. - Text**

Sate of DE, DDDS

Autism DE, PIC, DDDS

DHSS

treasurer

DDC

dhss

14 - What are your sources to better understand state disability/health policy information?

(Please check all that apply.)

**Websites. Please specify. - Text**

PIC of DE

Pa.gov dept of human services

Autism Speaks

**Social Media. Please specify. - Text**

Facebook

Facebook groups

**Other. Please specify. - Text**

So far, I've only dealt with issues regarding federal disability laws, so I guess I don't really have specific sources I turn to on the state level. Or at least, none that I can think of right now.

None

Not sure

Case worker

PRISE given time us at her IEP meeting (parental rights in special education

I need some!

N/a

15 - Is there anything else you would like to share in regards to sources of information you use for healthcare resources and/or policy information?

**Is there anything else you would like to share in regards to sources of information you use for healthcare resources and/or policy information?**

I would like to have a resource for healthcare and policy information. Possible attend a training session.

Again, the only thing I'd add is that I tend to pull from all sorts of sources when I'm looking for information or dealing with an issue related to healthcare, disability, medical, etc. There are times when I think it would be great if there was one central "hub" where I could go and then from there, do my research, access information and/or contact sources.

Other special needs parents are a great resource

No

OTHER PARENTS!! Hospital social workers, especially condition specific, but I only found out about them as a resource when my child was undergoing a big surgery.

Everything has been covered in this survey.

I will call the insurance agencies's customer service lines if I need clarification of anything related to their insurance.

None