

Initial Report

Support Services
Families Know Best - February 2017

1 - What is your place of residence?

#	Answer	%	Count
1	New Castle County, DE	69.57%	15
2	Kent County, DE	17.39%	4
3	Sussex County, DE	4.35%	1
4	Other - Pennsylvania Resident	4.35%	1
5	Other- New Jersey Resident	4.35%	1
6	Other- Maryland Resident	0.00%	0
	Total	100%	22

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

What is your child's disability or health condition?	Count
Autism	7
Down Syndrome	4
Traumatic Brain Injury	1
Learning Disability	1
Orthopedic impairment	1
Rett Syndrome	1
Type 1 Diabetes	1
Cerebral Palsy	1
Multiple:	5
Autism & ADHD	
ADHD and Anxiety	
Autism, Asthma, Sensory Processing Disorder	
Polymicrogyria - left hemiplegia, epilepsy, developmental delay	
Rare Genetic Disorder, Cerebral Palsy, Multiple Disabilities	

3 - Please identify yourself.

Answer	%	Count
Mother	95.00%	21
Father	0.00%	1
Legal Guardian	5.00%	0
Foster Parent	0.00%	0
Other (please specify)	0.00%	0
Total	100%	22

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

#	Answer	%	Count
1	White	86.96%	19
2	Black or African American	8.70%	2
3	American Indian or Alaska Native	4.35%	1
4	Asian	4.35%	1
5	Native Hawaiian or Pacific Islander	0.00%	0
6	Other	0.00%	0
	Total	100%	22

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

Answer	%	Count
Yes	65%	14
No	35%	8

No If response is No, please explain:

Medicaid will only pay for 30 day supply, although most of her meds are now maintained levels

Services and rxs no supplies are not covered

Medicaid does not adequately cover Dental needs. DS means undersized oral cavity and dental crowding. Health of mouth relates closely to risk for heart and other feeding problems

Our primary health insurance would never be adequate. Luckily we have Keystone First in PA as a supplement.

always seem to be fighting for items not covered, from more diaper supplies to durable medical equipment

No residential coverage available

you are restricted to providers within the network.

6 - Have you ever needed specialty health services for your child? (i.e. medical specialty, mental health services, telehealth services, etc.)

Answer	%	Count
Yes	78.26%	17
No	21.74%	5
Total	100%	22

6(a/c): Were you able to access the needed specialty health services?

Answer	%	Count
Yes	78%	13
No	22%	4

No. Please indicate which specialty health services you were unable to acce...

diapers through Medicaid are inadequate

Developmental pediatrician Specialists,

Difficulty obtaining ADA provider

Residential, life skills

What were the barriers in accessing the specialty health services?

appropriate diapers for over-active bladder issues; water proof mattress; Delaware has no places for autism and aggression

No participating providers

Lack of qualified personnel who will take insurance

Ins would not cover residential, and life skills isn't a service I could find

6b - Were the specialty health services adequate?

Answer	%	Count
Yes	100%	13
No	0%	0

No. Please explain:

7 - Have you ever needed in-home support services for your child?

Answer	%	Count
Yes	40.91%	9
No	59.09%	13
Total	100%	22

7(a/c) - Were you able to access the needed in-home support services?

Answer	%	Count
Yes	44%	4
No	56%	5

No. Please indicate which in-home support services you were unable to access...

staffing from different agencies aren't trained in autism aggression

ADA at home

Still waiting

My son was unable to get the needed speech, physical, and occupational therapy when he was in the early intervention services. We had signed up for services, but because of a shortage of therapists, we received either no or minimal actual services for each of these therapies.

What were the barriers in accessing the in-home support services?

staff training; time and availability issues (4-6 am)

Not covered

Lack of adequate insurance coverage

Waiting placement

Lack of therapists in Delaware (or so I was told).

7b - Were the in-home support services adequate?

Answer	%	Count
Yes	25%	1
No	75%	3

No. Please explain.

In home support was paid for by our school district when my daughter suffered a broken femur and could not be transported to school. The services were minimal.

We needed post-op PT and the agency's PTs were not available on many dates. When our Home Health Aide leaves, it takes months to find a peds replacement.

ABA therapy doesn't work for ALL autistics, some are too high functioning and manipulative

8 - Have you ever needed caregiver support services?

Answer	%	Count
Yes	27.27%	6
No	72.73%	16
Total	100%	22

8(a/c) - Were you able to access the needed caregiver support

Answer	%	Count
Yes	33%	2
No	67%	4

No. Please indicate which caregiver support services you were unable to acc...

Difficult to find overnight respite care for a non-verbal, non-mobile, multiple disability, seizure-disorder child.

Respite services are difficult to find and when they are located, the paperwork is extensive and confusing and we've been denied before for those services that are so desperately needed.

Respite. I have the funding, but nowhere to use it.

What were the barriers is accessing the caregiver supports?

Not covered

A facility that could provide the type of care my child would need for away from home respite or an in-home caregiver that could fulfill all of his requirements

Extensive & confusing paperwork. Denial for respite services. Any parent of a child with SN's should be able to access this! It's depressing and leaves the parents in complete despair to be denied. especially when some families chose to have one parent leave the work field due to the needs of a child with SN's...leads to severe burnout on the parental end.

8b - Were the caregiver supports adequate?

Answer	%	Count
Yes	50%	1
No	50%	1

No. Please explain.

I dont get enough hours when he is out of school

9 - Have you ever needed peer-to-peer support services?

Answer	%	Count
Yes	9.09%	2
No	90.91%	20
Total	100%	22

9a - Were you able to access the needed peer-to-peer support services?

Answer	%	Count
Yes	100%	2
No	0%	0

9b - Were the peer-to-peer support services adequate?

Answer	%	Count
Yes	100%	2
No	0%	0

10 - Have you ever needed educational support services for your child?

Answer	%	Count
Yes	68.18%	15
No	31.82%	7
Total	100%	22

10(a/c) - Were you able to access the needed educational support services?

Answer	%	Count
Yes	87%	13
No	13%	2

No. Please indicate which educational support services you were unable to a...

my son is going to a special school in PA; Delaware couldn't teach him functional communication

ADA

What were the barriers in accessing the education support services?

Delaware Autism Program inadequate in ABA therapy and functional communication training

Lack of available personnel

10b - Were the educational support services adequate?

Answer	%	Count
Yes	92%	12
No	8%	1

No. Please explain.

He only received a 504 plan and no testing accommodations through high school. We repeatedly requested testing accommodations due to his test anxiety and poor test results, even though he is extremely bright. DMA was not very receptive to this request.

11 - Have you ever needed social support services? (i.e. food, housing, transportation, etc.)

Answer	%	Count
Yes	13.64%	3
No	86.36%	19
Total	100%	22

11(a-c) - Were you able to access the needed social support services?

Answer	%	Count
Yes	67%	2
No	33%	1

No. Please indicate which social support services you were unable to access...No Response

What were the barriers in accessing the social service supports?

Not available

Were the social support services adequate?

Answer	%	Count
Yes	100%	2
No	0%	0

12 - Are there any other needed services you were able to access? Please specify the service and indicate if they were adequate.

Are there any other needed services you were able to access? Please specify...

Occupational therapy speech therapy

AI DuPont and Delaware Guidance Services continues to be the only services that are accessible for autism and challenging behaviors - my son loves that hospital

Community and informational resources - Delaware Family Voices, Family SHADE. Training - Delaware Family Voices. CP-specific resources/education sessions from AI duPont Trainings and disability resources - UD Center for Disability Studies..

Feeding therapy- it was a fight to get my child approved for the services through insurance. Kind of crazy. Sadly, it's seems to be how insurance companies work.

Respite, but it was not from ins

13 - Are there any other needed support services you were not able to access? Please specify the service and indicate the barriers to accessing the service.

Are there any other needed support services you were not able to access? P...

psychiatrist was hard but finally found Delaware Guidance Services

I would love to get periodic in-home care for my child so my husband and I could go out socially about once a month. I have been unsuccessful in this because most caregiver services require a weekly minimum of 16 hours. This is much more than what I need or want..

Recreational services - adequate options that meet his disabilities

We need services and don't even know where to turn, and not even his care coordinator at the ins can point us in right direction

I haven't been able to utilize DHSS funding for respite because I cant reach my family support person

14 - Is there any other information you would like to share in regards to support services?

Is there any other information you would like to share in regards to suppor...

There is some respite funding available through our county program (Chester County Mental Health/Intellectual & Developmental Disabilities Dept) however it is up to me to find a qualified caregiver and that is not always easy.

Most parents don't have the time or energy to hunt down resources - they need a directory or guide AND to be asked the right questions.

I see a lot of services available for low functioning or learning disabled Autistics, but NO services directed towards high functioning Autistics