

Initial Report

Mental/Behavioral Health Services
Families Know Best - June 2017

1 - What is your place of residence?

#	Answer	Count
1	New Castle County, DE	15
2	Kent County, DE	6
3	Sussex County, DE	2
4	Other - Pennsylvania Resident	1
5	Other- New Jersey Resident	1
6	Other- Maryland Resident	0
	Total	25

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

What is your child's disability or health condition?	Count
ASD	8
Down Syndrome	3
TBI	1
Intellectual disability	1
Cerebral Palsy	1
Orthopedic impairment	1
Rett Syndrome	1
Post traumatic stress disorder	1
Global development delay	1
Type 1 Diabetes	1
Multiple:	6
Polymicrogyria (hemiplegia, epilepsy , Dev delay)	
Rare genetic diagnosis, CP	
Autism, asthma, spd, immune deficiency	
Autism Spectrum Disorder; ADHD	
Autism, ADHD, PTSD,ODD	
Autism (also ADHD and OCD)	

3 - What is the age of your child?

#	Answer	Count
1	0-4 years old	2
2	5-11 years old	7
3	12-21 years old	14
4	over 21 years old	2
	Total	25

4 - Please identify yourself.

Please identify yourself.	Count
Mother	23
Father	1
Legal Guardian	1
Total	25

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

#	Answer	Count
1	White	21
2	Black or African American	0
3	Hispanic, Latino, or Spanish Origin	1
7	Asian	3
15	American Indian or Alaska Native	0
16	Native Hawaiian or Pacific Islander	0
17	Other (please specify)	0
	Total	25

6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs? (8/25 "No" responses)

If response is No, please explain:

Doesn't cover therapy, DME, or have participating providers

Not adequate coverage for sessions

Our primary insurance usually rejects equipment, therapies, diapers, g-tube supplies; however, Medicaid (secondary insurer) covers these costs.

Non traditional therapies such as massage, yoga, animal therapy would benefit him greatly but are not covered.

My son has needed a residential setting for many years to learn life skills he lost when he was transitioned to early into the normal public school system, neither his Medicaid nor his primary ins would cover these costs and it wasn't until the school district had exhausted all possibilities and agreed to pay for it that he is now receiving the high level care he's needed for 4 years

He had secondary Medicaid- Health Options. Through CCADP

Medicaid gives hard time in getting him therapies needed / week even though referring physician recommends it.

I wish Medical Marijuana was one of the existing Diagnosis that was covered.

7 - Have you ever needed to seek out mental/behavioral health services for your child (i.e. through a referral for these services or because of concerns you might have had in regards to your child's development)?

#	Answer	Count
1	Yes	14
2	No	11
	Total	25

8 - Were you able to obtain an initial consultation for mental/behavioral health services?

Answer	Count
Yes	10
No	4
Total	14

9 - How long did it take to be able to see the mental/behavioral health professional for the initial consultation? Yes responses...n=10

How long did it take to be able to see the mental/behavioral health profess...
3 months
4 months
close to a year
a month
week or two
6 months
2-3 weeks
depends on which time and which field - mental was not long at all but that dr left soon after and the nurse practitioner who took over totally messed up my sons meds and sent him into his first crisis.behavioral was much harder and took about 6-8 weeks because the company was just opening here in Delaware (from New Jersey)
Less than a month, but there were very limited providers and the one we found wasn't covered by insurance yet
2 months

10 - What were the barriers to obtaining the initial mental/behavioral health services consultation? No responses...n=4

What were the barriers to obtaining the initial mental/behavioral health se...

No participate providers and no coverage for non par

Waitlists for mental health specializing in autism- he is on several wait lists for months

My son is low functioning on the autism spectrum. He is functionally non-verbal and has no interest in art or ability to engage in imaginative play, so typical therapies will not work with him. 2) The one psychiatrist I know about who might be able to work with him has a waiting list of many months.

Grief counseling for a big verbal Autistic person

11 - Does your child have a mental health diagnosis?

Answer	Count
Yes	6
No	4
Total	10

12 - What is the diagnosis?

What is the diagnosis?

OCD

Autism

Autism spectrum disorder

Anxiety,

PTSD

PTSD, Mood disorder

13 - What services does your child require?

What services does your child require?

medication

community supports

ABA therapy; speech therapy

counseling medication

weekly therapy sessions with psychologist, an IEP and behavior plan in a special classroom under the direction of a trauma informed program

Psychiatry, family therapy, individual therapy, extra supports in school, and currently in a residential treatment center

14 - Have you been able to access these services in Delaware?

Answer	Count
Yes	5
No	1
Total	6

15 - Have you been able to access these services outside of Delaware?

#	Answer	Count
1	Yes	1
2	No	0
	Total	1

17 - Where are you receiving services (i.e. name of organization, location of organization)?

Where are you receiving services (i.e. name of organization, location of or...

CNMRI

POW&R

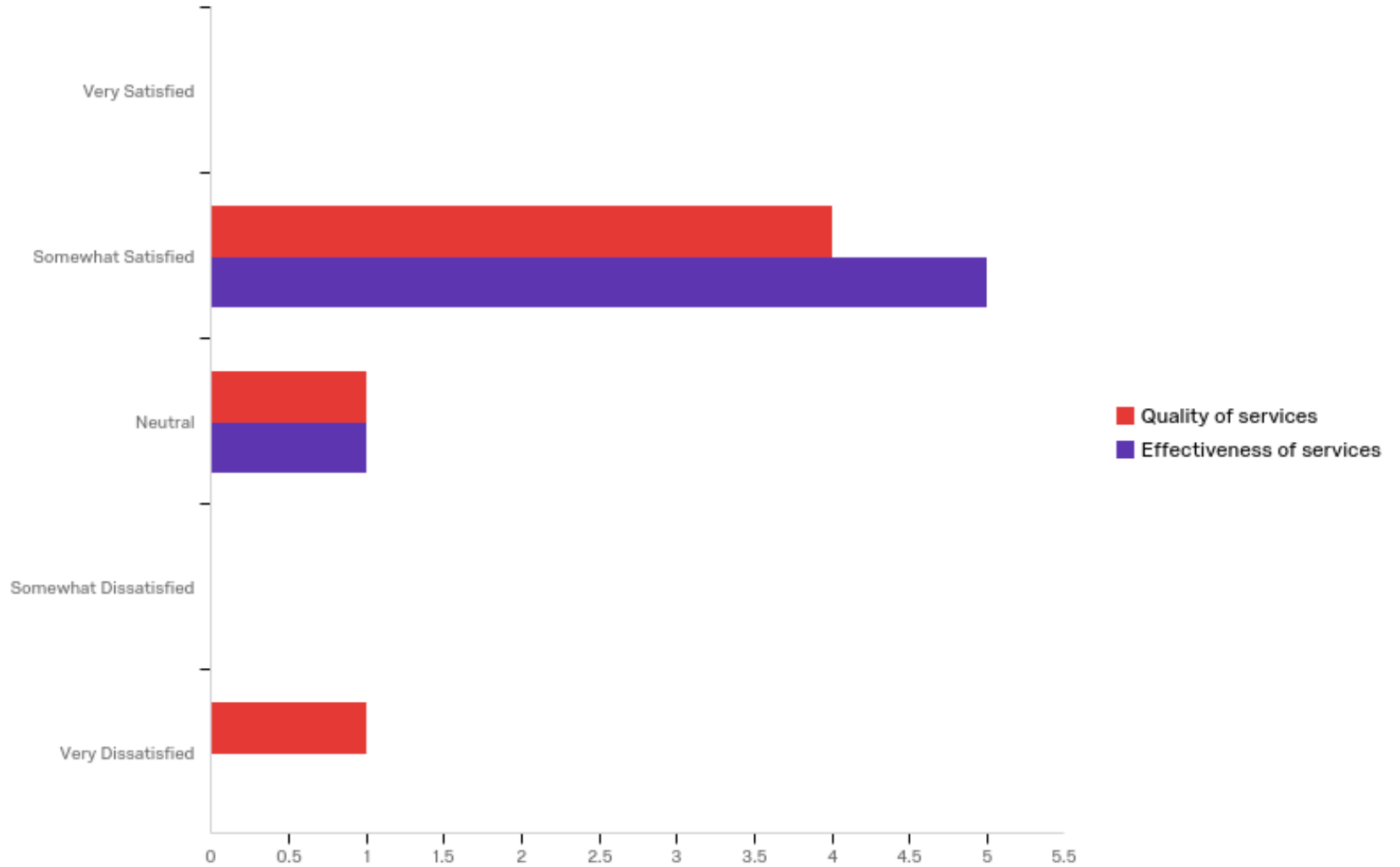
Brandywine Center for Autism- Milford Campus; Central Delaware Speech & Language

Christiana Care & Behavior Health Associates

Private physician, education through pathways at Stubbs elem

Foundations Behavioral Health

18 - How would you rate the quality/effectiveness of the services you have received?



19 - Does your insurance cover mental/behavioral health services for your child?

Answer	Count
Yes	6
No	0
Total	6

20 - Does your mental/behavioral health professional accept your insurance?

Answer	Count
Yes	6
No	0
Total	6

21 - What needs does your child have that you feel are currently unmet?

What needs does your child have that you feel are currently unmet?

Needs therapy and treatment

Grief counseling... they just want to use pharmacy

quality support personnel

Have had problems in the past with BCBS covering 100% of the ABA therapy sessions for Daniel

Social supports and the alternative therapies previously mentioned, a case manager would be helpful

Life skills are the major component his lacking, also proper social skills and stress:anger management

situational anxiety- parents are separated and divorcing and the family/child needs support with the transition

Appropriate day care for when I am at work and his school is not in session. He is a teenager, non-verbal, and aggressive. It would be dangerous for all concerned to have a home health aid -- or anyone else -- alone with him. I can't afford to have him go to someplace like the Brandywine Center for Autism; he currently gets ABA therapy after school paid for by insurance; I'm afraid that if I asked insurance to pay for the entire days that I have to work, they would not only refuse (saying that I am looking for babysitting rather than ABA therapy), but would also subsequently deny the after-school daily ABA therapy.

22 - Is there any other information you would like to share in regards to mental/behavioral health services for your child?

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

we have been doing a trial and error method with medication and still working to find a balance.

We have been with doc for 2+ years but was hard to find then and she is not aware of other services in area to refer for additional support. Centralized intake and or continuum of care is needed

There are absolutely NO places in Delaware for a High IQ HIGH functioning but angry violent Autistic to go and be treated, its as if NO ONE in this state has ever seen one, not his dr's, therapists or teachers

the social worker at AI hospital was very helpful with resources, unfortunately, nothing has opened up yet

I am the subject of my son's physical abuse daily. I got to the point where I thought it best to find alternate living arrangements for him, but none are available: He is making satisfactory academic progress according to his IEP goals, so a residential school is not a possibility, and he is a minor, so there are no group homes available. My son is now bigger, stronger, and faster than me, and I no longer dare take him out into the community, and I daily fear for both of our safety. I hope and pray that I'll be able to keep us both alive until he turns 18 and can go into a group home, but I really wish there were some sort of residential services available before then.