

Initial Report

Behavioral and Mental Health Education/Crisis Intervention Needs

Families Know Best - June 2021

1 - What is your place of residence?

Answer	Count
New Castle County, DE	18
Kent County, DE	7
Sussex County, DE	2
Other - Pennsylvania Resident	1
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	29

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

Answer	Count
Autism Spectrum Disorder	10
Cerebral Palsy	2
Diabetes	1
Down syndrome	3
Traumatic Brain Injury	1
Other (please specify):	4
Multiple disabilities (please specify):	8
Total	29

4 - Please identify yourself.

Answer	Count
Mother	25
Father	3
Legal Guardian	1
Foster Parent	0
Other (please specify):	0
Total	29

3 - What is the age of your child?

Answer	Count
0-4 years old	0
5-11 years old	6
12-21 years old	20
over 21 years old	3
Total	28

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

Answer	Count
White	21
Black or African American	4
Hispanic, Latino, or Spanish Origin	2
Asian	3
American Indian or Alaska Native	1
Native Hawaiian or Pacific Islander	0
Other (please specify):	0
Total	31

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

Answer	Count
Yes	21
No (please explain below):	8
Total	29

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

6_2_TEXT - No (please explain below):

No (please explain below): - Text

Nurse shortage

It really needs to cover more physical skills support, like personal training. He doesn't qualify for physical therapy anymore but he still needs assistance with exercise and physical skills training, but as the parent I cannot continue to be the one doing that.

My primary health insurance denies coverage for services that are clearly medically necessary.

Not enough nursing or care support .

Aquatherapy and horse riding therapy not available at all places

No coverage or providers for extreme mental health/ behavioral health problems.

No residential options for severe kiddos with aggression.

No options.

We came to a decision to enroll our son in an expensive therapeutic 18-mo. program, and insurance didn't pay a dime.

There are no real things to help him available

I'd have to say No since I still have a horrible time finding appropriate therapy and services for a high functioning 17 year old with Autism!

7 - Do you feel you would benefit from a series of free informative Zoom seminars/workshops focused on autism spectrum disorder (ASD) and related neurodevelopmental disorders, such as intellectual disability (ID) and developmental disability (DD), as they pertain to behavioral and mental health challenges?

Answer	Count
No	13
Yes. Please archive for later viewing.	9
Yes	7
Total	29

8 - What training topics are most important to you? (Check all that apply)

Answer	Count
Mental and Behavioral Health - What services does Delaware offer to families in crisis?	19
Interacting with First Responders during a Behavioral or Mental Health Crisis	10
Does Delaware need an ASD/ID/DD specific in-patient family centered mental health unit?	9
Pharmaceutical Treatment Best Practice Q and A Session	6
Overview of Child Protective Services	2
Other. Please specify.	6
Total	52

8 - What training topics are most important to you? (Check all that apply)

Other...Please specify. - Text
High functioning Autism
None
A few years back, I *desperately* needed information on what Delaware offered to families in crisis, but I struggled to find my own way through a crisis situation. My son is currently living at Foundations Behavioral Health in Pennsylvania.
Transition help, big tests accommodations
ABA and what interventions have been studied and shown to be most effective for those with ASD
Benefits we are eligible for

9 - Is your child currently taking prescription medication for behavioral or mental health diagnoses (Bipolar, Anxiety, ADHD, Schizophrenia, OCD, ODD, PANDAS, Other?)

Answer	Count
Yes	12
No	17
Total	29

10 - Has your child been aggressive or violent in the past year?

Answer	Count
Once	5
Daily	3
Weekly	2
Monthly	5
None of the above.	14
Total	29

11 - In the past year have you worried about your safety, the safety of your child or the safety of others due to mental health and behavior needs of your ASD, ID DD child?

Answer	Count
Yes	11
No	18
Total	29

12 - How often, in the past year, were you worried about safety?

Answer	Count
Daily	2
Weekly	2
Monthly	4
Other...Please specify.	3
Total	11

12 - How often, in the past year, were you worried about safety?

12_4_TEXT - Other...Please specify.

Other...Please specify. - Text

From time to time but not specific. An example is after he almost drowned in the pool. I worry he is not always conscious and can unintentionally hurt himself.

In the past year, but not so much anymore.

Everytime my son goes to work (just started working 2 months ago and I know he's talking to people about stuff he shouldn't, my friends and his coworkers have told me so), he's socially not ready because we have not been giving enough services to support his social growth

13 - In the past year, have you called 911 for assistance in de-escalating aggressive behavior?

Answer	Count
Yes	1
No	28
Total	29

14 - How often, in the past year, have you called 911 for assistance in de-escalating aggressive behavior?

Answer	Count
Daily	1
Weekly	0
Monthly	0
Other. Please specify.	0
Total	1

15 - When you called 911, were you satisfied with the response you received?

Answer	Count
Yes	1
No	0
Total	1

16 - Are you currently looking for placement options due to behavior or mental health needs?

Answer	Count
Yes	2
No	27
Total	29

17 - Have you placed your child in a treatment or residential facility outside of Delaware due to behavior or mental health needs?

Answer	Count
Yes	7
No	22
Total	29

18 - Was the placement in the last year?

Answer	Count
Yes	2
No	5
Total	7

19 - Were you satisfied with the placement and services received?

Answer	Count
Yes	5
No. Please explain.	2
Total	7

19 - Were you satisfied with the placement and services received?

No. Please explain. - Text

No real solutions

The staff at these places are disgusting, they treat your child like dirt and leave them to fend off the other patients that are even worse off than they are.

My son speaks of being hit by a staff member, I believe it- because I myself was in the same type of placement as a child and as an adult and saw abuse happen, I was locked in a room refused medical treatment and lied to about pregnancy blood work being done and coming back negative- just so I would take the meds they wanted me to, so I took the meds left the hospital 3 days later and immediately got tested and

I was Pregnant and told them

Meds I had taken would be detrimental to my fetus.

The staff at most of these places cannot be trusted with our children's lives. They are not paid enough to properly be compensated for what they have to deal with, so they don't do the job well because they know they are being under paid and over worked.

They get feces thrown at them, they get hit and bit, cursed at and so much worse.

The pay for workers at residential placement need to be paid a hazard pay type amount

20 - Did you know there is a mobile crisis unit available in Delaware to help de-escalate aggressive or dangerous episodes?

Answer	Count
Yes	14
No	15
Total	29

21 - What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

Families are handling things with their child the best they can and not to assume we are being abusive

This info is not always available in spanish, the chief of police released a statement of the services they offer to the community but ,we need it in more languages.

N/a

There is much Delaware needs to learn and add. I'd like them to know that our current mobile crisis system for kids and adults is mental health based, talk therapy. Talk therapy is not indicated, or effective, for most people with ASD. Our mobile crisis programs do not have any BCBA's on staff and don't have specialized training in behavioral approaches, which is the approach necessary for treatment of problem behavior in ASD. We have no higher level of care programs in DE (day treatment, inpatient) that focus on behavior or neurobehavioral, like Kennedy Kreiger's NBU. We need that here, and more training and understanding around the state for what behavioral services are and how they differ from mental health counseling. Parents of kids with ASD have been concerned for years that when their child with ASD needs crisis services, and may find themselves in DE inpatient mental health, that there are no behavior analysts there and so the treatment is often not effective. They come back home and the issue is not resolved.

The child typically cannot control how they are behaving and the parents are doing the best they can. It's important that first responders be aware of this and be ready to intervene and take the child to the hospital asap vs. asking too many questions in the home. Make sure the child is safe first. THEN, ask questions once the child is in a safe place.

21 - What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

access to decision makers quickly so you don't get stuck in the bureaucracy while in crisis.

Support staff availability is so low because of the pay they get/hour. Support coordination should not be given to agencies rather it should be family self-directed services

n/a

Everyone has unique needs that have to be individually addressed

Patience

There should be appropriate knowledge and interventions for first responders dealing with behavioral issues in people with developmental disabilities

That they love their children and truly want the best for them. No two days are the same. Having the tools to succeed and see their children grow is optimal. Please know these parents at time may be hard on themselves and don't always know how to cope or manage when overwhelmed. These families are human and all are growing separately and collectively at the same time.

N.a

The current infrastructure is not equipped to handle, let alone adequately treat our loved ones. Legislators, first responders, and CPS need to be educated on the aggressive, scary ASD, and stop generalizing to the quirky, fun, just different propaganda that is being spewed all over the place. Legislators need to start planning, and creating services for adults, day and residential facilities. THINK LONG TERM.

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What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

That it's not always a matter of "who's to blame." Yes, sometimes there's a culprit. But many times, there isn't. It's important to address the situational crisis of the moment without shaming or blaming in advance of getting a more complete picture. I feel that parents get a lot of this ("if only that person was raised right" and "weren't they taught the proper way to behave?").

We do not have a child with autism or behavioral needs that would involve first responders or child protective services

Stop treating us like we are child abuser and help us with healthy options. And quit prosscouting Childeren with mental issue and implementing fines instead of finding real ways to help make change in their lives

NA

For several months, until I could finally convince "the system" that my son's aggressions were literally putting both of our lives in danger, I thanked God every night that my son didn't kill me (and, by extension, kill himself, since if I were incapacitated, he would not have the wherewithal to take care of himself.) It was only after a home visit from his school followed by a new patient visit to a psychiatrist -- during both of which my son became quite aggressive -- that my concerns were finally taken seriously. I had tried every agency I could think of. I even called the Domestic Violence hotline and was told that it was not their bailiwick since the aggressor was my son rather than my partner. We both very nearly died because we fell between the cracks. (Originally, the school said that since my son's aggression wasn't interfering with his schoolwork, it wasn't their problem. DDDS said that because he was a minor, they could do nothing.)

21 - What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

That the family is often suffering from PTSD like symptoms themselves due to living with the uncertainty the client's behavior creates.

How to de-escalate.

None

Each family needs different support

NA

NO

Parents who deal with these type of aggressive behaviors develop anxiety, depression, PTSD and other mental health disorders. There is also a guilt stigma that can trigger a deep depression that could mean contemplating suicide and contemplating ending it all. Also a trigger could mean you blackout and accidentally hurt your child. This is serious and a lot families are dealing with this with no avenue for help. A process needs to be developed to help families quickly. Waiting on the school district and an ICT process takes too long to get the families assistance that is need most urgently to protect the child, siblings and the whole family from abuse.

21 - What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

What do you feel is important for legislators, first responders, and child protective services to know about families living with autism and behavioral mental health needs?

They need understanding and compassion and much more support from the medical community in Delaware.

PLEASE PLEASE PLEASE know this---

If a hospital/residential placement option becomes available in Delaware, for ALL the patients safety and growth-

Make sure that there is a HIGH FUNCTIONING WARD! High Functioning Autism children should not be placed with lower functioning children in a closed personal setting/living situation.

Our High functioning Autism children are in need of help, and when you group them with children who are more lower functioning, they lose the individual attention they need, it also can set off their problems worse and then the behaviors being treated are situational instead of the problems they came in with.

My son is 17 now, for 17 years I have not been able to find HIGH functioning help his whole life.

This state has failed my son

That behavioral mental health should be elevated to the same level as physical health. Mental health issues are not only a concern for autism and children with disabilities, but are at the center of alcoholism, drug addiction, alot of gun violence and even serial killers. There should be mental health professionals responding to 911 calls involving mental heath and not just police officers

22 - What training topics do you feel would benefit your family situation?

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variety of safety/behavior techniques or options available

What options families have , to understand what they are signing when there children are admitted In a mental health facility. Mental health laws and court . What being committed in a mental health facility . What to expect in the event a family member is admitted in a mental health facility.

Benefits like respite etc we qualify for
Transitioning into adulthood

See above. Thanks for asking!

How to keep your other children safe; How to keep your home safe (locking away knives, meds, guns, etc)

available resources for lower functioning individuals with autism.

self redirectiona nd supoort coordinator agencies work

n/a

Dealing with stereotypy (stims)

22 - What training topics do you feel would benefit your family situation?

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How to defuse situations

None needed for our situation

Helping parents parents children with Autism and other disabilities effectively and ways to support in areas of discipline. So that parents are better equipped and are able to effectively de-escalate any issues.

N.A

-Who to call when your child gets violent (****Please stop referring everyone to Autism DE. It is a joke, give real resources.)

-What providers really take nonverbal kids with behavioral challenges

-what adult services are available for this demographic

-respite providers for these children and adults (no one is being served if parents are being abused and are burnt out)

****Please stop referring everyone to Autism DE. It is a joke, give real resources.

Our family is healing and healthier now, but back when we were in the thick of it, it would have been helpful to have people who understood the behaviors particular to our son (who we eventually found out had RAD), and could direct us to the appropriate resources. We had no clue.

22 - What training topics do you feel would benefit your family situation?

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Our issue is epilepsy and medications used to treat it and their behavioral side effects

Information on mental issues and things available to actually help instead of trying to find fault in parents actions and giving over worked under paid therapist who work situations makes it almost impossible for them to even be helpful

NA

My son will likely be at FBH until age 21. When he transitions back to Delaware, not only will he be going into a group home, he will also be needing a whole new medical team (since he will have aged out of his old one), not to mention something to do during his days. I would love to have information on how to find doctors who would work with people like him (nonverbal and sometimes aggressive), as well as ideas for easing his transition into adulthood. Many of the services that are offered in Delaware (such as Pathways) wouldn't work with my currently-out-of-state son. Once again, we seem to be falling between the cracks. I would love to hear how to navigate services when the child's legal and physical residences are in different states.

No suggestions

Topics about what help is available locally.

22 - What training topics do you feel would benefit your family situation?

What training topics do you feel would benefit your family situation?

None

How to talk to a child with asd

NA

NI

Behavioral training and bringing folks in from different organizations on how to be happy and change your attitude with a child with challenging behaviors.

Social skill training for older teens

I can't think of any at this time.