

Initial Report

Respite Care Update

Families Know Best - June 2019

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

Answer	Count
Attention Deficit Hyperactivity Disorder	1
Autism Spectrum Disorder	8
Cerebral Palsy	0
Diabetes	1
Down syndrome	3
Epilepsy	0
Traumatic Brain Injury	1
Other (please specify):	4
Multiple disabilities (please specify):	4
Total	22

1 - What is your place of residence?

Answer	Count
New Castle County, DE	14
Kent County, DE	3
Sussex County, DE	2
Other - Pennsylvania Resident	2
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	22

4 - Please identify yourself.

Answer	Count
Mother	19
Father	2
Legal Guardian	0
Foster Parent	0
Other (please specify): Maternal grandmother/Legal guardian	1
Total	22

3 - What is the age of your child?

Answer	Count
0-4 years old	1
5-11 years old	10
12-21 years old	9
over 21 years old	2
Total	22

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

Answer	Count
White	16
Black or African American	3
Hispanic, Latino, or Spanish Origin	0
Asian	2
American Indian or Alaska Native	1
Native Hawaiian or Pacific Islander	0
Other (please specify):	2
Total	24

Other (please specify): - Text

I am white; my child is adopted from China.

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

Answer	Count
Yes	16
No (please explain below):	6
Total	22

No (please explain below): - Text

My child has significant needs and it appears that the company operates off of hard fast rules, regardless of the diagnosis.

They denied OT by another provider, and for him to be seen at Kennedy Krieger when Nemours has openly said they can't help him.

Yes, because we have primary insurance through my husband's work, and secondary insurance through Medicaid. Our primary insurance is not adequate on its own.

When we needed certain therapy's or help we couldn't receive it.

In the end My son needed residential placement for a yr and insurance does not pay for that

Needs to cover ABA better and also cover some personalized, support physical fitness. He cannot just go to the local gym, but needs continued gross motor skills instruction.

With Medicaid as her secondary insurance, coverage is adequate. If she had only our primary, Cigna, it would not be sufficient.

Things not covered

7 - Do you know what respite means?

Answer	Count
Yes	21
No	1
Total	22

8 – The following is a definition of respite from the ARCH National Respite Network and Resource Center:

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

For more information about respite from ARCH, please click here: <https://archrespite.org/>.

9 - Do you know about funding sources for respite care?

Answer	Count
Yes. Please list sources of which you are aware.	11
No	11
Total	22

Yes. Please list sources of which you are aware. - Text
DDDS
DDDS
DDDS
DDDS
Easter Seals DDDS DAP
EASTER SEALS
DAP, DDDS
Chester county MH/ IDD department
Delaware Respite Care Network, Easter Seals
DDDS, Brennen School provides (not guaranteed) respite services at a discount. Easter Seals offers scholarships for Camp Fairlee Manor
Presumptive eligibility, ester seal

10 - Have you ever sought out respite services?

Answer	Count
Yes	11
No	11
Total	22

11 - In what circumstances have you sought out respite services? (Check all that apply)

Answer	Count
Enable work outside the home	5
Relieve emotional stress/parent burnout	7
Attend to the needs of other family members	5
Attend to personal needs (social/business/recreational/medical)	8
Complete household tasks/chores	6
Participate in caregiver support/training	4
Emergency situation	4
Other (please specify):	2
Total	41

Other (please specify): - Text

When needed to be away from home but could not take my son

travel without child

12 - In what setting did you seek to receive respite services? (Check all that apply)

Answer	Count
In-home	9
Out-of-home	6
Other (please specify):	0
Total	15

13 - Were you able to access and use respite services?

Answer	Count
Yes	9
No	2
Total	11

14 - What were the barriers to accessing respite services?

What were the barriers to accessing respite services?
no caregiver availability
I had been able to get respite services sometimes when my son was young (under age nine or so), but as he got older and his behaviors proved more challenging, I could not find anyone willing to provide respite.

15 - What financial sources did you use for your respite services? (Check all that apply)

Answer	Count
Out of pocket personal account	5
Community social service agency (please specify):	3
Federal, state or local government agency (please specify):	3
Coverage from recipient's insurance policy	2
Volunteer program (please specify):	1
Other (please specify):	1
Total	15

15 - What financial sources did you use for your respite services? (Please specify)

Community social service agency (please specify): - Text

DDDS

DDDS Funding

Del Respite Care, Easter Seals

Federal, state or local government agency (please specify): - Text

Delaware developments disabled services

Easter seals

County department

Volunteer program (please specify): - Text

Embrace

Other (please specify): - Text

Baby sitters from community

16 - How frequently do you use respite care services? (Select one choice)

Answer	Count
Daily	0
Weekly	2
Monthly	2
Occasionally (vacation, emergency situation)	3
Seasonally (summer or winter breaks)	0
Other (please specify):	2
Total	9

Other (please specify): - Text
As needed And available
2-3 times per year for 4-6 hours

17 - Within the last 12 months, which of the following best describes your experience with respite services:

Answer	Count
Received respite as scheduled from a paid or unpaid person or agency	6
Did not receive respite as scheduled from a paid or unpaid person or agency	0
Placed on a waiting list for services	0
Had funding, however could not find a qualified provider	0
Referred to another agency or program	0
Other (please specify):	3
Total	9

Other (please specify): - Text

Waiting on repayment now for services provided last month, it's stressful to wait and wait and wait to be repaid and then sometimes find out the service dates may not have even been submitted correctly

Used family members to pay for respite because of trouble finding a respite person/place

Not approved

18 - In general, how did you learn about the respite services that you received?
 (Check all that apply)

Answer	Count
Federal, state or local government agency	1
Community social services agencies	1
Physician or other medical professional	0
Informal networking (friends, family, faith based organization, support group, etc.)	7
Internet, telephone directory (please specify):	0
Other (please specify):	2
Total	11

Other (please specify): - Text

Years ago My son and I were observed by another mother and she saw how much my son needed me constantly and how stressed I was and she took my cell phone number and texted me the contact information and explained to me the program and that she felt I needed some respite time before I burnt out

Google search

19 - In general, who provided you with respite services? (Check all that apply)

Answer	Count
Paid family member	6
Unpaid family member	2
Paid friend/neighbor	1
Unpaid friend/neighbor	1
Volunteer	1
Paid staff	1
After school program	1
Staff from child's school	1
Nurse/other professional	2
Summer camp	1
Other (please specify):	3
Total	20

Other (please specify): - Text

UCP of De has respite at camp time and for school breaks (spring/Christmas)

Not applicable

babysitters

20 - Is the amount of respite services you receive meeting your needs?

Answer	Count
Yes	3
No (please explain):	6
Total	9

No (please explain): - Text

BUT my adult daughter just moved to New Orleans so I have lost my main respite provider and it devastated my son

Not enough caretakers

I have three children with disabilities currently not one agency alone is able to provide respite services for all three children due to their different disability diagnosis. I can usually find services for one child and then make arrangements

but when he was younger it was not enough and we really needed support to find a private provider when his family member could not do it

It is difficult to find providers

It's difficult to find someone to meet his needs, if one of the parents goes away and we need extra hours covered, it quickly goes through the funds

21 - Were you satisfied with the quality of the respite services you have received?

Answer	Count
Yes	4
No (please explain):	5
Total	9

No (please explain): - Text

Home help/ nursing agencies's staffing is unreliable. There are a lot of no-shows, lateness and people I don't feel comfortable leaving my child with.

There is a shortage, so they make you very aware that you should be thankful for anyone who comes, despite how bad they might be.

I am satisfied but I need more people to do this not just my family (daughters) because I want them to go places with me.

Quality? I hired friends not any professional organization so I cannot speak as to the quality however I am grateful for the financial assistance that I did receive when I was approved previously

Used nurse who already knew my daughter from school setting

yes with the family members/friends/babysitters but it is difficult to find people who can lift our son at 120 lbs, give medication, and meet his vast needs the way we would if we were with him

22 - I have not sought respite services because: (Check all that apply)

Answer	Count
I am able to provide adequate care to my loved on without assistance.	3
I have enough assistance and do not need respite services.	2
I have family or friends to ask for help.	4
My child won't stay with someone he/she does not know.	1
I am concerned or have difficulty with outsiders caring for my child.	3
I do not know where to find services.	4
I do not have funding to pay for care.	4
I think I do not qualify.	3
Services are too difficult to obtain.	2
My child requires too much specialized care.	0
I haven't found a trusted provider yet.	0
Other (please specify):	1
Total	27

Other (please specify): - Text

Don't know what it is or if we need it

23 - If funding were NOT an issue, how would you want respite provided? (Check all that apply)

Answer	Count
In-home	13
At an after-school program	8
At a Saturday respite program	9
Overnight at my house	5
Overnight away from home	7
Weekend/week-long camp	8
Other (please specify):	3
Total	53

Other (please specify): - Text
Programs I could take my child to I.e. dance class, therapeutic horseback riding
Still don't know what it is
Scheduled and unscheduled school closures like brakes holidays and snow closures

24 - If there was a trained volunteer who could provide respite, would you use one?

Answer	Count
Yes	9
Maybe	11
No	2
Total	22

25 - Do you care for an aging parent or an adult with a disability as well as your child(ren)?

Answer	Count
Yes	8
No	14
Total	22

26 - Is there any other information you would like to share in regards to respite care services?

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wish there were additional respite resources available

In our case, we would need a respite provider who is fluent in ASL.

Waiting for repayment can be almost as stressful as having a special needs child. It's very hard to put out example/ 300\$ out of pocket and not be repaid at a specific time and have to wait and pray the check comes out of pocket

We need a respite facility in Delaware for people with intellectual disabilities and senior citizens

Services for relatives keeping together and taking care of sibling units due to parental abuse or drugs or social services, especially grandparents

my son doesn't use respite as much now, but it was a huge need and issue when he was younger (and up to age 14ish). There are no private providers around here. Luckily we had family that would help but for those that don't, I don't know how they survive. Not just anyone can watch our kids. We need providers with training and heart. And we do need a break from caregiving! Respite shouldn't be so difficult. And then we met other parents along the way who didn't even know respite was a thing!

Respite services are so needed! Friends and family do try to help but we'd be able to do more with skilled respite providers caring for our child.

Everything has been covered in this survey.

My son is nonverbal, so I would ideally prefer the respite to have two adults present at all times; unfortunately, in the past eight years, I couldn't find even a single person to provide respite locally. (Camp Fairlee Manor was my lifeline and the only respite provider who would accept my son.)