

Initial Report

Transition Services Update

Families Know Best - September 2019

1 - What is your place of residence?

Answer	Count
New Castle County, DE	14
Kent County, DE	4
Sussex County, DE	2
Other - Pennsylvania Resident	3
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	24

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

Answer	Count
Attention Deficit Hyperactivity Disorder	0
Autism Spectrum Disorder	11
Cerebral Palsy	1
Diabetes	1
Down syndrome	2
Epilepsy	0
Traumatic Brain Injury	1
Other (please specify):	2
Multiple disabilities (please specify):	6
Total	24

3 - What is the age of your child?

Answer	Count
0-4 years old	1
5-11 years old	9
12-21 years old	12
over 21 years old	2
Total	24

4 - What is your child's race/ethnicity?

Answer	Count
White	18
Black or African American	6
Hispanic, Latino, or Spanish Origin	1
Asian	2
American Indian or Alaska Native	1
Native Hawaiian or Pacific Islander	0
Other (please specify):	1
Total	29

Other (please specify): - Text

Bi-Racial

5 - Please identify yourself.

Answer	Count
Mother	23
Father	1
Legal Guardian	0
Foster Parent	0
Other (please specify):	0
Total	24

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

Answer	Count
White	18
Black or African American	4
Hispanic, Latino, or Spanish Origin	0
Asian	2
American Indian or Alaska Native	1
Native Hawaiian or Pacific Islander	0
Other (please specify):	0
Total	25

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

Answer	Count
Yes	15
No (please explain below):	9
Total	24

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

No (please explain below): - Text

It does for the most part. But some of the services and events i would like my daughter be apart, they have no type of coverage i would have to pay up front out of pocket before i might get reimbursed by medicaid. I know with events at autism of delaware. But i haven't never tried it so i know sure how easy the process is.

Primary (commercial) insurance is grossly inadequate. Only with Medicaid can we provide what my child needs.

Some services are not covered and co-pays are expensive

Wish it covered some professional physical fitness...it's hard to keep doing PT as they get older, but they need to be active. I wish it covered personal trainer, someone with knowledge about muscle groups and those with different abilities

It does not cover lot of provides in the area.

No ins covered residential facilities

My son makes us of Practice Without Pressure for his dental work. He often needs multiple visits for routine care; each visit costing in the triple digits. Insurance will pay for a single dental visit, but will not pay for multiple ones, nor will it pay for the additional support services he needs.

Does not cover out of state—PA and Maryland has better autism services, and we are constantly denied, despite Delaware doctors and specials saying they are unable
To help out child

No coverage for things we need, no participating providers

9 - Is your child 14 or older?

Answer	Count
Yes	13
No	11
Total	24

10 - At what age would you expect to receive information from your child's health care provider about your child transitioning from a pediatric to adult health care services?

At what age would you expect to receive information from your child's health care provider about your child transitioning from a pediatric to adult health care services?

Before she turns 18 or 19 years old.

10

16

16

14

I dont know

21

17

10

18

16

11 - Does your child currently receive Medicaid benefits?

Answer	Count
Yes	7
No	4
Total	11

12 - Do you know at what age your child's Medicaid coverage ends?

Answer	Count
Yes	1
No	6
Total	7

13 - Does your child's health care provider have information about community resources?

Answer	Count
Yes	7
No	4
Total	11

14 - Does your child's health care provider respect how your customs and beliefs affect your care?

Answer	Count
Yes	9
No	2
Total	11

15 - Is your child's primary care provider a pediatrician?

Answer	Count
Yes	9
No. My child's primary care provider is a ...	4
Total	13

My child's primary care provider is a ...

Family doctor

Physician assistant

General practitioner, specializing in Down Syndrome

My son is between PCPs. His pediatrician retired and he is currently living at a residential facility with medical care. He may be returning home to live in October, and I have no idea who will be his PCP at that time.

16 - Did your child's primary health care provider discuss with you, or have an office policy that informed you, at what age your child may need to change to a new provider who treats mostly adults?

Answer	Count
Yes	6
No	3
Total	9

17 - Would a discussion about doctors who treat adults been helpful to you?

Answer	Count
Yes	3
No	0
Total	3

18 - Does your child have medical specialists who see only children?

Answer	Count
Yes	8
No	5
Total	13

19 - Has any medical specialist discussed transition to an adult provider for when your child ages out of pediatric care?

Answer	Count
Yes	5
No	3
Total	8

20 - Would a discussion about specialists who treat adults been helpful to you?

Answer	Count
Yes	3
No	0
Total	3

21 - Eligibility for health insurance often changes as children reach adulthood. Have any of your health care providers discussed with you how your child can obtain or keep some type of health insurance coverage as he/she becomes an adult?

Answer	Count
Yes	4
No	9
Total	13

22 - Would a discussion about health insurance been helpful to you?

Answer	Count
Yes	9
No	0
Total	9

23 - Do you know about possible benefits for which your young adult may be eligible? (Medicaid, Social Security Income, SSDI, etc.)

Answer	Count
Yes	12
No	1
Total	13

24 - Does your child currently receive Medicaid benefits?

Answer	Count
Yes	10
No	3
Total	13

25 - Do you know at what age your child's Medicaid coverage ends?

Answer	Count
Yes	3
No	7
Total	10

26 - How often do your child's doctors or other health care providers encourage, and actively work with your child, to gain skills and take responsibility for (his/her) health care needs, such as taking medication and their side effects, understanding (his/her) diagnosis, knowing what to do in an emergency or following medical advice?

Answer	Count
Never	7
Sometimes	4
Always	2
Total	13

27 - Did your child's health care provider actively work with your child to think about and plan for the future (ex. take time to discuss future plans about education, work, relationships, and development of independent living skills)?

Answer	Count
A lot	1
Some	3
A little	1
Not at all	8
Total	13

28 - Did your child's health care provider actively work with your child and you to create a written plan to meet his/her health goals and needs?

Answer	Count
Yes	2
No	11
Total	13

29 - Did the health care provider create and share your child's medical summary with your child and you?

Answer	Count
Yes	10
No	3
Total	13

30 - Did your child's health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?

Answer	Count
Yes	5
No	8
Total	13

31 - Did your child's health care provider have information about community resources?

Answer	Count
Yes	4
No	9
Total	13

32 - Did your child's health care provider respect how your customs and beliefs affect your care?

Answer	Count
Yes	8
No	5
Total	13

33 - What questions do you have in regards to your child transitioning from pediatric to adult health care services?

What questions do you have in regards to your child transitioning from pediatric to adult health care services?

What age will she consider for transitioning to an adult health care provider? Will i also still be able to get different community resources to help us if a situation comes up we need assistance with?

What doctors are covered under his insurance

Services , cost

How will I pay for services

NOt sure

when do you start the process, and there is a template to guide you through the process

She will still need to see multiple specialists - would we have a case manager to help coordinate her care? Now we try to stay within the CHOP system for all of her doctors so they can easily access each other's information

None. Still a ways away.

Residential options

Day program options

And most importantly, how these options can be covered and paid for

Someone who will be flexible and see beyond the diagnosis

Will my child still get the same level of medical treatment?

34 - What would have helped to better prepare your child for health care transition?

What would have helped to better prepare your child for health care transition?

Starting from an earlier age to know the options.

more attention from the government

Specific referrals (Names & contact info) for various specialists she will need. I am only given non-specific info about hospital affiliations rather than specific doctors.

Also, there is no one who seems clear about whether Medicaid coverage crosses state lines. For example, we live in PA and receive Medicaid as my daughter's secondary insurance. Right now, we see pediatric doctors at Al DuPont in DE. They seem to know about doctors for adult patients who practice in DE, specifically at Christiana. Can we see those doctors or must we transition to PA doctors for adult care?

Hoping there is still time

providers being more knowledgeable; having adult providers in our area who also know disabilities

Discussion with doctor and staff

Not completely sure, I'm overwhelmed by it all

My son turns 18 in about three weeks, and I have no idea where he will be living at that time (the ICT process to determine this has just begun), or who his doctors will be. At this point, knowing these things would be tremendously beneficial.

none

a "cheat sheet" of resources available, reminders from doctors about important steps to be taken toward transition, coordination with school and hospital social workers

Anything at all

Find a provider who knew how to deal with complicated health issues

35 - Please feel free to share any other information or concerns regarding transition.

Please feel free to share any other information or concerns regarding transition.

My son is nonverbal and has severe cognitive challenges; even if he currently had a PCP, and even if said hypothetical doctor would be willing to take the time to speak with him, he would almost certainly not understand the doctor. As mentioned in an earlier question, many of these questions really do not apply in our situation.

This survey helped me to figure out questions for my child's next visit. He will be transitioning in 2 years

more attention from the government

Post 21 Agency are not adequately prepared to support our students, especially if they have any type of mental health concerns.