Initial Report

Transition Services Update
Families Know Best - September 2019
1 - What is your place of residence?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Castle County, DE</td>
<td>14</td>
</tr>
<tr>
<td>Kent County, DE</td>
<td>4</td>
</tr>
<tr>
<td>Sussex County, DE</td>
<td>2</td>
</tr>
<tr>
<td>Other - Pennsylvania Resident</td>
<td>3</td>
</tr>
<tr>
<td>Other- New Jersey Resident</td>
<td>1</td>
</tr>
<tr>
<td>Other- Maryland Resident</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
</tr>
</tbody>
</table>
2 - What is your child's disability or health condition?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention Deficit Hyperactivity Disorder</td>
<td>0</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>11</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>0</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>1</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>2</td>
</tr>
<tr>
<td>Multiple disabilites (please specify):</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
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3 - What is the age of your child?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 years old</td>
<td>1</td>
</tr>
<tr>
<td>5-11 years old</td>
<td>9</td>
</tr>
<tr>
<td>12-21 years old</td>
<td>12</td>
</tr>
<tr>
<td>over 21 years old</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
</tr>
</tbody>
</table>
4 - What is your child's race/ethnicity?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>18</td>
</tr>
<tr>
<td>Black or African American</td>
<td>6</td>
</tr>
<tr>
<td>Hispanic, Latino, or Spanish Origin</td>
<td>1</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>0</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>

**Other (please specify):** - Text

Bi-Racial
5 - Please identify yourself.

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>23</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Legal Guardian</td>
<td>0</td>
</tr>
<tr>
<td>Foster Parent</td>
<td>0</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>
### 6 - What is your race/ethnicity? (Check all that apply)

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>18</td>
</tr>
<tr>
<td>Black or African American</td>
<td>4</td>
</tr>
<tr>
<td>Hispanic, Latino, or Spanish Origin</td>
<td>0</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islandan</td>
<td>0</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>
7 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No (please explain below):</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
</tr>
</tbody>
</table>
**No (please explain below):**

- It does for the most part. But some of the services and events I would like my daughter to 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 providers 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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
</tr>
</tbody>
</table>

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?

Before she turns 18 or 19 years old.

10
16
16
14
I don't know
21
17
10
18
16
11 - Does your child currently receive Medicaid benefits?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
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</tbody>
</table>
13 - Does your child's health care provider have information about community resources?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>
15 - Is your child's primary care provider a pediatrician?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No. My child’s primary care provider is a ...</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>
19 - Has any medical specialist discussed transition to an adult provider for when your child ages out of pediatric care?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5</td>
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<tr>
<td>No</td>
<td>3</td>
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<td>Total</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
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</tbody>
</table>
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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
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</tbody>
</table>
24 - Does your child currently receive Medicaid benefits?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
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</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
</tr>
</tbody>
</table>
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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>7</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4</td>
</tr>
<tr>
<td>Always</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
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</tbody>
</table>

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)?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lot</td>
<td>1</td>
</tr>
<tr>
<td>Some</td>
<td>3</td>
</tr>
<tr>
<td>A little</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>
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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2</td>
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<tr>
<td>No</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>
31 - Did your child's health care provider have information about community resources?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
</tbody>
</table>
33 - What questions do you have in regards to your child transitioning from pediatric to adult health care services?

<table>
<thead>
<tr>
<th>What questions do you have in regards to your child transitioning from pediatric to adult health care services?</th>
</tr>
</thead>
<tbody>
<tr>
<td>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?</td>
</tr>
<tr>
<td>What doctors are covered under his insurance</td>
</tr>
<tr>
<td>Services, cost</td>
</tr>
<tr>
<td>How will I pay for services</td>
</tr>
<tr>
<td>Not sure</td>
</tr>
<tr>
<td>When do you start the process, and there is a template to guide you through the process</td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>None. Still a ways away.</td>
</tr>
<tr>
<td>Residential options</td>
</tr>
<tr>
<td>Day program options</td>
</tr>
<tr>
<td>And most importantly, how these options can be covered and paid for</td>
</tr>
<tr>
<td>Someone who will be flexible and see beyond the diagnosis</td>
</tr>
<tr>
<td>Will my child still get the same level of medical treatment?</td>
</tr>
</tbody>
</table>
34 - What would have helped to better prepare your child for health care transition?

<table>
<thead>
<tr>
<th>What would have helped to better prepare your child for health care transition?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starting from an earlier age to know the options.</td>
</tr>
<tr>
<td>more attention from the government</td>
</tr>
<tr>
<td>Specific referrals (Names &amp; 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 AI 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?</td>
</tr>
<tr>
<td>Hoping there is still time</td>
</tr>
<tr>
<td>providers being more knowledgable; having adult providers in our area who also know disabilities</td>
</tr>
<tr>
<td>Discussion with doctor and staff</td>
</tr>
<tr>
<td>Not completely sure, I’m overwhelmed by it all</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>none</td>
</tr>
<tr>
<td>a &quot;cheat sheet&quot; of resources available, reminders from doctors about important steps to be taken toward transition, coordination with school and hospital social workers</td>
</tr>
<tr>
<td>Anything at all</td>
</tr>
<tr>
<td>Find a provider who knew how to deal with complicated health issues</td>
</tr>
</tbody>
</table>
Please feel free to share any other information or concerns regarding transition.

<table>
<thead>
<tr>
<th>Please feel free to share any other information or concerns regarding transition.</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>This survey helped me to figure out questions for my childs next visit. He will be transitioning in 2 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>more attention from the government</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post 21 Agency are not adequately prepared to support our students, especially if they have any type of mental health concerns.</th>
</tr>
</thead>
</table>