Initial Report

Medicaid Benefits and Services
Families Know Best - March 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>16</td>
</tr>
<tr>
<td>Kent County, DE</td>
<td>4</td>
</tr>
<tr>
<td>Sussex County, DE</td>
<td>4</td>
</tr>
<tr>
<td>Other - Pennsylvania Resident</td>
<td>2</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>27</td>
</tr>
</tbody>
</table>
2 - What is your child's disability or health condition?

<table>
<thead>
<tr>
<th>What is your child's disability or health condition?</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>9</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>1</td>
</tr>
<tr>
<td>Rett Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>1</td>
</tr>
<tr>
<td>Type 1 Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Mental and behavioral issues</td>
<td>1</td>
</tr>
<tr>
<td>mild intellectual disability</td>
<td>1</td>
</tr>
<tr>
<td>Development delay</td>
<td>1</td>
</tr>
<tr>
<td>Other (not specified)</td>
<td>3</td>
</tr>
<tr>
<td>Multiple:</td>
<td>6</td>
</tr>
<tr>
<td>autism, severe developmental delays</td>
<td></td>
</tr>
<tr>
<td>Autism, asthma</td>
<td></td>
</tr>
<tr>
<td>Rare genetic disorder, CP</td>
<td></td>
</tr>
<tr>
<td>Polymicrogyria - hemiplegia, epilepsy, dev delay</td>
<td></td>
</tr>
<tr>
<td>CP, seizures</td>
<td></td>
</tr>
<tr>
<td>Epilepsy and ADHD</td>
<td></td>
</tr>
</tbody>
</table>
### 4 - Please identify yourself.

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>24</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
</tr>
<tr>
<td>Legal Guardian</td>
<td>1</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>27</strong></td>
</tr>
</tbody>
</table>
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>13</td>
</tr>
<tr>
<td>12-21 years old</td>
<td>11</td>
</tr>
<tr>
<td>over 21 years old</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
</tr>
</tbody>
</table>
5 - 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>20</td>
</tr>
<tr>
<td>Black or African American</td>
<td>6</td>
</tr>
<tr>
<td>Hispanic, Latino, or Spanish Origin</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>0</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>1</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
</tr>
</tbody>
</table>
6 - 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>21</td>
</tr>
<tr>
<td>No (please explain below):</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
</tr>
</tbody>
</table>

No (please explain below): - Text

The services the insurance provides that not meet the needs of the child, and have to be supplemented by all the different support agencies within the state.

Our primary insurance alone, Cigna, is definitely not adequate. Usually having Medicaid as a secondary is adequate, however I am finding that Cigna is denying coverage more often. No providers, no coverage, everything needs prior authorization

Our insurance is not affordable enough.

My son needed placement in a residential setting and neither of his ins would cover it so he didn’t receive the help he desperately needed until the state was involved thru his school.
7 - Does your child currently receive benefits or services through Medicaid?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>21</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
</tr>
</tbody>
</table>

8 - For which services are you currently using Medicaid? (Check all that apply.)

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical services</td>
<td>16</td>
</tr>
<tr>
<td>Therapies (i.e. physical therapy, occupational therapy, speech pathology, etc.). Please specify.</td>
<td>11</td>
</tr>
<tr>
<td>Dental services</td>
<td>10</td>
</tr>
<tr>
<td>Medical transportation services</td>
<td>1</td>
</tr>
<tr>
<td>Incontinence supplies</td>
<td>7</td>
</tr>
<tr>
<td>Other. Please specify.</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
</tr>
</tbody>
</table>
For which services are you currently using Medicaid? (Check all that apply.)

**Q31_2_TEXT - Therapies (i.e. physical therapy, occupational therapy, speech pathology, etc.). Please specify.**

- Can not access a provider willing to accept medicaid or waitlist is extensive
- Outpatient PT
- PT, Speech and feeding and hypotheraphy
- Speech, occupational
- OT, PT, Speech

**Q31_7_TEXT - Other. Please specify.**

- My son is currently in an out-of-state residential facility. Because of this, we aren't using Medicaid services at the moment. When he is at home, though, we use Medicaid as his secondary insurance for medical services and therapies
- Nursing
- Pulmonologist, allergist, immunologist, genetic doctor, hematologist
- DME
9 - Is Medicaid your child's primary or secondary insurance?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>8</td>
</tr>
<tr>
<td>Secondary</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

10 - With which Medicaid Managed Care Organization is your child currently enrolled?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highmark/Blue Cross Blue Shield of DE</td>
<td>20</td>
</tr>
<tr>
<td>AmeriHealth Caritas Delaware</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
11 - Have you ever had to change your Medicaid Managed Care Provider?

<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>12</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

12 - Was this change by choice or due to the managed care provider no longer offering benefits?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changed by choice.</td>
<td>3</td>
</tr>
<tr>
<td>Managed care provider no longer offered benefits. Please explain.</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
</tr>
</tbody>
</table>

11_4_TEXT - Managed care provider no longer offered benefits. Please explain.

Managed care provider no longer offered benefits. Please explain. - Text

| Left Practice | We used to have Diamond State |
13 - Was the transition to another managed care provider a smooth one?

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No. Please explain.</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
</tr>
</tbody>
</table>
14 - Are you familiar with the Children's Community Alternative Disability Program through the Delaware Division of Medicaid & Medical Assistance?

<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>17</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
</tr>
</tbody>
</table>

15 - Does your child receive Medicaid coverage through the Children's Community Alternative Disability Program?

<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>2</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
</tr>
</tbody>
</table>