Title V Reporting: Youth Transition Survey

Children and Youth With Special Health Care Needs Program
Overview

● This survey was designed to evaluate young adults’ experiences with transitioning from pediatric to adult primary care providers, and evaluate the impact of the COVID-19 pandemic on transitioning and utilizing health care

● The survey was disseminated electronically among Children and Youth with Special Health Care Needs program partners as well as the Title V Family Delegate and her connections through the Partnership for People with Disabilities

● The survey was additionally distributed electronically among students at four universities throughout the state of Virginia: Old Dominion University, Virginia Commonwealth University, Virginia Military Institute, and the University of Virginia

● Due to a partnership with a University of Virginia student, this survey was very likely responded predominantly by members of the UVA student body
Survey Questions

Health Care Survey - Transition from pediatric to adult health care

The Virginia Department of Health (VDH) would like to learn more about the experiences and needs of youth transitioning from pediatric medical care and life to adult medical care and life. Youth ages 14-22 and/or their parents are asked to complete this brief survey to provide input to help inform VDH strategies in this area.

Please follow the screens to complete the survey below. There are three screens/pages in this survey. Don’t forget to finish to the end to receive an Amazon gift card (first 200 respondents)

Thank you for your participation!

This is an optional survey about your experience changing from pediatric to adult health care. Your responses are confidential and anonymous.

Kindly indicate your respondent status:

- Parent, guardian, or proxy of an adolescent (ages 14-22)
- Young adult (ages 18-22)

How old is your child?

- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22

How old are you?

- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22

Have you been diagnosed with any of the following conditions? (Check all that apply)

- Sickle Cell Disease
- Cystic Fibrosis
- Cerebral Palsy
- Congenital Heart Defect
- Muscular Dystrophy
- Spina Bifida
- Bleeding Disorder (hemophilia, von Willebrand, etc)
- Hearing/Visual Impairment
- Fetal Alcohol Syndrome
- Asthma
- Diabetes
- Down Syndrome
- organ transplant
- Feeding issues (g-tube or NG-tube dependent)
- Severe disability
- Traumatic brain injury
- Orthopedic injury
- Autism Spectrum Disorder
- Oppositional Defiant Disorder (ODD)
- Anxiety/Depression
- Bipolar Disorder
- Severe emotional disturbance
- Learning disorder
- Intellectual Disability
- Speech or Language Impairment
- Other health impairment not listed above (genetic, ADHD, medical, etc.)
- None / Not applicable

Other, please specify:

Receive services from any of the following programs? (Check all that apply)

- Care Connection for Children
- Bleeding Disorders or Hemophilia Clinic
- Sickle Cell Clinic
- Family Navigators
- Local Health Department
- Child Development Clinic
- Federally Qualified Health Center
- Other pediatric medical specialty clinic
- None
Survey Questions Continued

A primary care provider is your main doctor or provider who manages most of your medical issues. You’ll go to your primary care provider for your yearly physical exam and preventive health care. A primary care provider can be a physician, physician assistant (PA), or nurse practitioner (NP).

Did your primary care provider talk to [pronoun] about changing to a new doctor who treats mostly adults?

Very Prepared  Somewhat prepared  Not prepared  Not applicable

If you are a parent, please answer the following for your child

[pronoun] primary care provider make appointments with [your] primary care provider?

Does [pronoun] primary care provider help [pronoun] learn how to manage [pronoun] medications (e.g., track [pronoun] medications and their side effects, know what to do in an emergency)?

Does [pronoun] primary care provider spend time to discuss future plans (e.g., education, work, relationships, and development of independent living skills)?

Does [pronoun] primary care provider actively work with [your] to create a written plan to meet [your] health goals and needs for adult care?

Does [pronoun] primary care provider explain legal changes in privacy, decision making, and consent that take place at age 18?

Thank you for completing the survey. Once you click submit, you will be taken to a form to enter your information to receive an Amazon e-gift card. Your responses will remain anonymous and will not be linked to your information for the gift card.
Respondent Demographics
<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total respondents</td>
<td>152</td>
</tr>
<tr>
<td>Youth between ages 18-22</td>
<td>84.9%</td>
</tr>
<tr>
<td>Youth aged 19</td>
<td>26%</td>
</tr>
</tbody>
</table>

These numbers include both young adults reporting on their experience, as well as parents reporting on behalf of their children's experience.
Respondent Overview

- Out of 152 respondents:
  - 33 respondents were parents reporting on behalf of their child
  - 119 young adults replied on behalf of their own experience

<table>
<thead>
<tr>
<th>Age of Young Adult</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent on Behalf of Child</strong></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>5</td>
</tr>
<tr>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>19</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td><strong>Young Adult</strong></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>19</td>
<td>37</td>
</tr>
<tr>
<td>20</td>
<td>25</td>
</tr>
<tr>
<td>21</td>
<td>31</td>
</tr>
<tr>
<td>22</td>
<td>8</td>
</tr>
</tbody>
</table>
Age Groups of Youth Represented

- Unknown Age: 1, 14.5%
- 10-17: 22, 14.5%
- 18-22: 129, 84.8%
### Race and Ethnicity of Youth Represented

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>36.2%</td>
</tr>
<tr>
<td>White who also noted Non-Hispanic ethnicity</td>
<td>91.5%</td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>25.0%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>18.4%</td>
</tr>
<tr>
<td>Black</td>
<td>13.2%</td>
</tr>
</tbody>
</table>
Race/Ethnicity of Youth Represented and Percent of Respondents Within Each Category

- NH White: 36.2% (54 respondents)
- NH Asian: 25.0% (37 respondents)
- NH Black: 18.4% (27 respondents)
- Hispanic: 13.2% (20 respondents)
- NH Two or More Races: 5.9% (8 respondents)
- Prefer Not to Answer: 3.9% (5 respondents)
- NH Native Hawaiian/Pacific Islander: 0.7% (1 respondent)
Due to a partnership with a University of Virginia student, this survey was very likely responded by students among the UVA community. To compare with demographics of survey respondents, Table 1a shows the race and ethnicity breakdown of the student body.

Table 1a: Demographics of UVA Student Body

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percent of Undergraduate Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>52.31%</td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>18.06%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>7.02%</td>
</tr>
<tr>
<td>Non-Hispanic Multi-Racial</td>
<td>5.69%</td>
</tr>
<tr>
<td>Non-Hispanic Native American/Alaskan Native</td>
<td>0.05%</td>
</tr>
<tr>
<td>Non-Hispanic Hawaiian or Pacific Islander</td>
<td>0.05%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7.06%</td>
</tr>
<tr>
<td>Unknown</td>
<td>4.91%</td>
</tr>
<tr>
<td>Non-resident</td>
<td>4.85%</td>
</tr>
</tbody>
</table>
Demographics of Youth Represented Ages 18-22

Table 1b: Demographics of College-Aged Youth Represented

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Number of Youth Represented Ages 18-22</th>
<th>Percent of Youth Represented Ages 18-22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>41</td>
<td>31.8%</td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>37</td>
<td>28.7%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>21</td>
<td>16.3%</td>
</tr>
<tr>
<td>Non-Hispanic Multi-Racial</td>
<td>8</td>
<td>6.2%</td>
</tr>
<tr>
<td>Non-Hispanic Hawaiian or Pacific Islander</td>
<td>&lt;5</td>
<td>***</td>
</tr>
<tr>
<td>Hispanic</td>
<td>16</td>
<td>12.4%</td>
</tr>
<tr>
<td>Prefer Not to Answer</td>
<td>&lt;5</td>
<td>***</td>
</tr>
</tbody>
</table>

This comparison was made to evaluate whether or not survey respondents align with the demographic breakdown of UVA students. The Non-Hispanic Black and Asian populations have a higher representation in the survey than at UVA, while Non-Hispanic White respondents have lower representation.

*** Indicates the percentage has been suppressed due to a numerator of less than 5
Diagnoses
163 diagnoses reported

Anxiety/depression was the most common diagnosis reported

21.7% of all youth represented noted having anxiety or depression

73% of youth represented with anxiety/depression were ages 18-22

The second most common diagnosis was “other health impairment”

65 respondents noted no diagnosis
Overview of Diagnoses*

*This does not reflect the number of respondents with diagnoses; 65 respondents reported "no diagnosis" while other respondents had more than one diagnosis.
Top 5 Diagnoses by Race and Ethnicity
Race and Ethnicity of Youth Represented with Anxiety/Depression and Percent of Total With This Diagnosis

- NH White: 14 (42.4%)
- NH Black: 6 (18.2%)
- NH Asian: 6 (18.2%)
- Hispanic: 4 (12.1%)
- Prefer Not to Answer: 1 (3.0%)
- NH Two or More Races: 1 (3.0%)
- NH Native Hawaiian/Pacific Islander: 1 (3.0%)
Race and Ethnicity of Youth Represented with “Other Health Impairment” and Percent of Total With This Diagnosis

- **Non-Hispanic White**: 13, 54.2%
- **Non-Hispanic Black**: 4, 16.7%
- **Hispanic**: 4, 16.7%
- **NH Two or More Races**: 2, 8.3%
- **NH Asian**: 1, 4.2%
Race and Ethnicity of Youth Represented with Asthma and Percent of Total With This Diagnosis

- NH White: 7 (31.8%)
- NH Black: 6 (27.3%)
- NH Asian: 6 (27.3%)
- Hispanic: 2 (9.1%)
- NH Two or More Races: 1 (4.5%)
Race and Ethnicity of Youth Represented with Intellectual Disability and Percent of Total With This Diagnosis

9
81.8%

8
18.2%

White

Hispanic
Race and Ethnicity of Youth Represented with Sickle Cell Disease and Percent of Total With This Diagnosis

- NH Black: 9 (90.0%)
- Hispanic: 1 (10.0%)

Race and Ethnicity of Youth Represented with Speech or Language Impairment and Percent of Total With This Diagnosis

- NH Black: 8 (80.0%)
- NH White: 1 (10.0%)
- Hispanic: 1 (10.0%)
Services Received
37 youth represented received a total of 44 different services

163 diagnoses reported among 66 youth represented
Services Received by Youth Represented

- None: 116
- Other Pediatric Medical Specialty Clinic: 15
- Federally Qualified Health Center: 1
- Child Development Clinic: 0
- Local Health Department: 9
- Family Navigators: 1
- Sickle Cell Clinic: 5
- Bleeding Disorders or Hemophilia Clinic: 2
- Care Connection for Children: 11
Youth represented who **did/did not receive services from specific programs**

- **116** noted no receipt of services. **45.7%** (53 out of 116) of these respondents **did** have a diagnosis of some kind
- **58%** of youth represented with **“other medical diagnosis”** did not receive services
- **68%** of youth represented with **asthma** did not receive services
- **54.5%** of all youth represented with anxiety/depression did not receive services
- **20.5%** of youth represented with a diagnosis received help from a local health department
Primary Care Providers
91.4% of youth represented (139 out of 152) stated that they have a Primary Care Provider (PCP).

Out of those that have a PCP, only 24.5% (34 out of 139) reported their doctor speaking with them about transitioning to a doctor who treats adults.

Slightly less than half (47.1%) of providers who mentioned transitioning followed up with identifying a new provider.
The majority of youth represented (54.6%) felt at least somewhat prepared to change to an adult care provider.

71.9% of youth represented indicated some level of speaking individually with their PCP, without parents present.

58.7% of youth represented said they always, very often, or sometimes scheduled their own appointments.

69.6% of youth represented indicated their provider helping them manage medications at least sometimes.
“Does your primary care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?”

56% (57 out of 101*) of youth represented over age 18 had discussed legal changes with their provider

81% (4 out of 22) of youth represented under age 18 had not discussed legal changes to take place at age 18

*this total is based on the number of respondents in this age group that have a PCP
“Do you know how you will become insured as you become an adult?”

48% of all youth represented knew how they would be insured as they became an adult.

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage Knowing How to Be Insured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under age 18</td>
<td>26%</td>
</tr>
<tr>
<td>Over age 18</td>
<td>51.9%</td>
</tr>
</tbody>
</table>
Impact of COVID-19 on transitioning to adult care

42.1% of youth represented stated that they attended appointments solely in-person during the COVID-19 pandemic.

7.2% stated that they attended appointments virtually only.

39.5% stated that they attended virtually and in-person.
Key Themes Surrounding the Impact of the Pandemic on Transition Experience

Themes are listed top to bottom from most to least commonly reported

- Limited appointment availability leading to less accessible medical care
- Increased isolation and depression due to social distancing
- Switch to telehealth viewed as both positive and negative
- Fear caused people to avoid seeing the doctor
- Delayed transition to adult provider, went without care for months or years
- Limited money to pay for health care
Key Findings:

The importance of connections with students in gaining an understanding of the experience of transitioning from pediatric to adult primary care.

Mental health is an integral part of comprehensive primary health care.

There is an opportunity for provider education regarding the importance of discussing transition with patients.
Limitations

● Lack of broad sample size

● Status as a current college student or working adult was not noted in the survey; this would provide insight as to specific experiences among different populations within the young adult demographic group

● Question regarding anxiety/depression did not clarify if this existed prior to transition or coincided with transition period

● No inclusion of a mental health or write-in category for “services received”
Opportunities

● Develop relationships with students across other universities in Virginia for greater representation of different respondent groups

● Partnering with universities regarding transition

● Provide a broader list of services received in the next survey

● Include mental health in transitioning healthcare for a more comprehensive approach to health care

● Further research about causes of anxiety and type of anxiety

● Start discussions surrounding co-occurring special health conditions with mental health