

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

Page 1

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)

Page 6

How old is your child?

How old are you?

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

[havehas] [pronoun] 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
- Organ transplant
- Feeding issue (g-tube or NG-tube dependent)
- Seizure disorder
- 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:

[verb] [pronoun] 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

Page 7

[verb] [pronoun] have a primary care provider? Yes
 No

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? Yes
 No

Did [pronoun2] primary care provider assist in identifying a new adult provider to transfer to? Yes
 No

[verb] [pronoun] feel prepared to change to an adult health care provider? Very Prepared
 Somewhat prepared
 Not prepared
 Not applicable

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

	Always	Very Often	Sometimes	Rarely	Never
[verb] [pronoun] talk with [theyour] primary care provider alone, while [pronouns3] [areis3] not in the room?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[verb] [pronoun] schedule [theyour] own appointments with [theyour] primary care provider?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
--	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Does [pronoun2] primary care provider help [pronoun] learn how to manage [theyour] medications (e.g. know [pronoun2] medications and their side effects, know what to do in an emergency)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
--	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Does [pronoun2] primary care provider take time to discuss future plans (e.g., education, work, relationships, and development of independent living skills)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
---	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Does [pronoun2] primary care provider actively work with [pronoun] to create a written plan to meet [theyour] health goals and needs for adult care? Yes
 No
 Don't Remember

Does [pronoun2] primary care provider explain legal changes in privacy, decision-making, and consent that take place at age 18? Yes
 No
 Don't Remember

Page 8

Does [pronoun2] primary care provider create and share [theyour] medical summary with [pronoun] and [pronouns3]? Yes
 No
 Don't Remember

[verb] [pronoun] know how [youthey] will be insured as [youthey] become an adult? Yes
 No

How hard has the COVID-19 pandemic impacted [pronoun2] transition experiences? (i.e., in terms of equity, made access easier, made access harder, etc.)

Easier No change Harder

(Place a mark on the scale above)

Based on your last answer, please explain how the COVID-19 pandemic impacted [pronoun2] transition experiences? (i.e., in terms of equity, made access easier, made access harder, etc.) _____

How [dodoes2] attend appointments with [theyour] primary health care provider during the COVID-19 Pandemic? In-person visits only
 Virtual visits only
 In-person and Virtual visits
 None
 Other

What is [pronoun2] race? Black or African American
 Asian
 Native Hawaiian/Pacific Islander
 Native American/Alaskan Native
 White
 Two or More Races
 Prefer not to answer

[areis2] Hispanic/Latino or of Spanish origin? Yes
 No
 Prefer not to answer

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

Overview of Youth Represented

152 total
respondents

84.9%
represent
youth
between
ages 18-22

26%
represent
youth aged
19

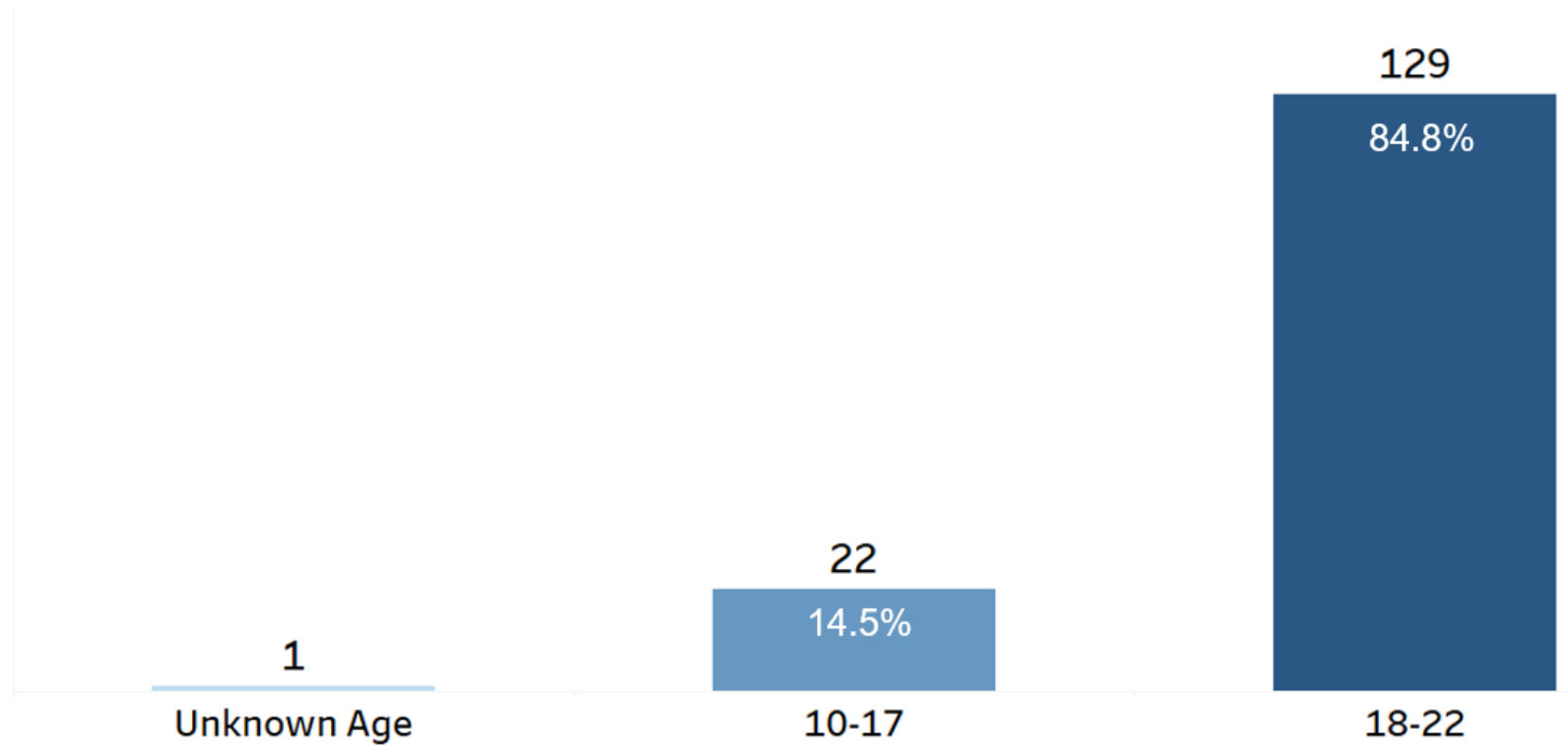
These numbers include both young adults reporting on their experience, as well as parents reporting on behalf of their children's experience

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

Age of Young Adult	Count
<i>Parent on Behalf of Child</i>	
14	8
15	5
16	4
17	5
18	2
19	3
20	3
21	2
<i>Young Adult</i>	
18	18
19	37
20	25
21	31
22	8

Age Groups of Youth Represented



Race and Ethnicity of Youth Represented

36.2% of respondents identified as Non-Hispanic White

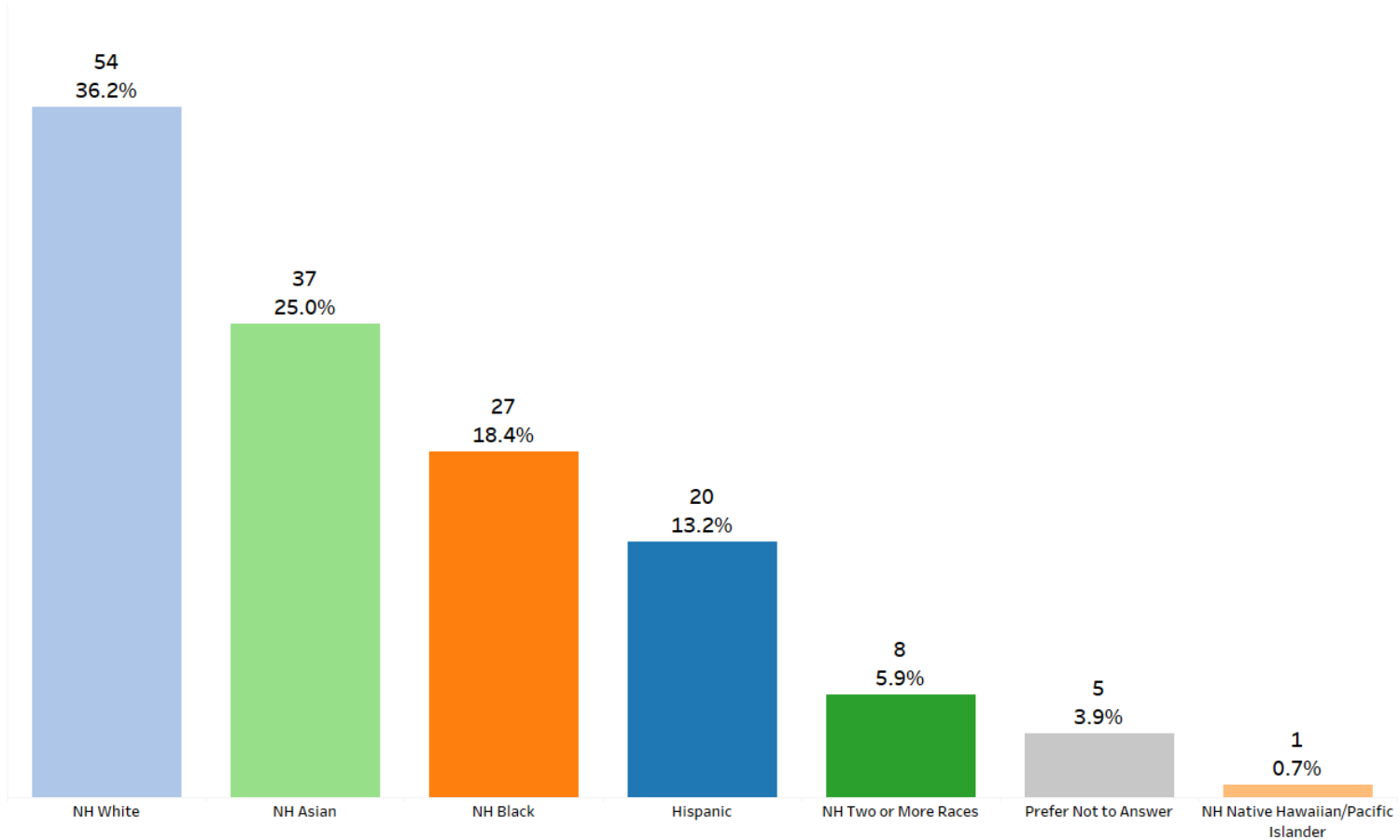
91.5% of the respondents who identify as White also noted Non-Hispanic ethnicity

25.0% of respondents identified as Non-Hispanic Asian

18.4% identified as Black

13.2% of respondents identified as Hispanic or Latino

Race/Ethnicity of Youth Represented and Percent of Respondents Within Each Category



Demographics of University of Virginia

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

Race/Ethnicity	Percent of Undergraduate Population
Non-Hispanic White	52.31%
Non-Hispanic Asian	18.06%
Non-Hispanic Black	7.02%
Non-Hispanic Multi-Racial	5.69%
Non-Hispanic Native American/Alaskan Native	0.05%
Non-Hispanic Hawaiian or Pacific Islander	0.05%
Hispanic	7.06%
Unknown	4.91%
Non-resident	4.85%

Demographics of Youth Represented Ages 18-22

Table 1b: Demographics of College-Aged Youth Represented

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

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

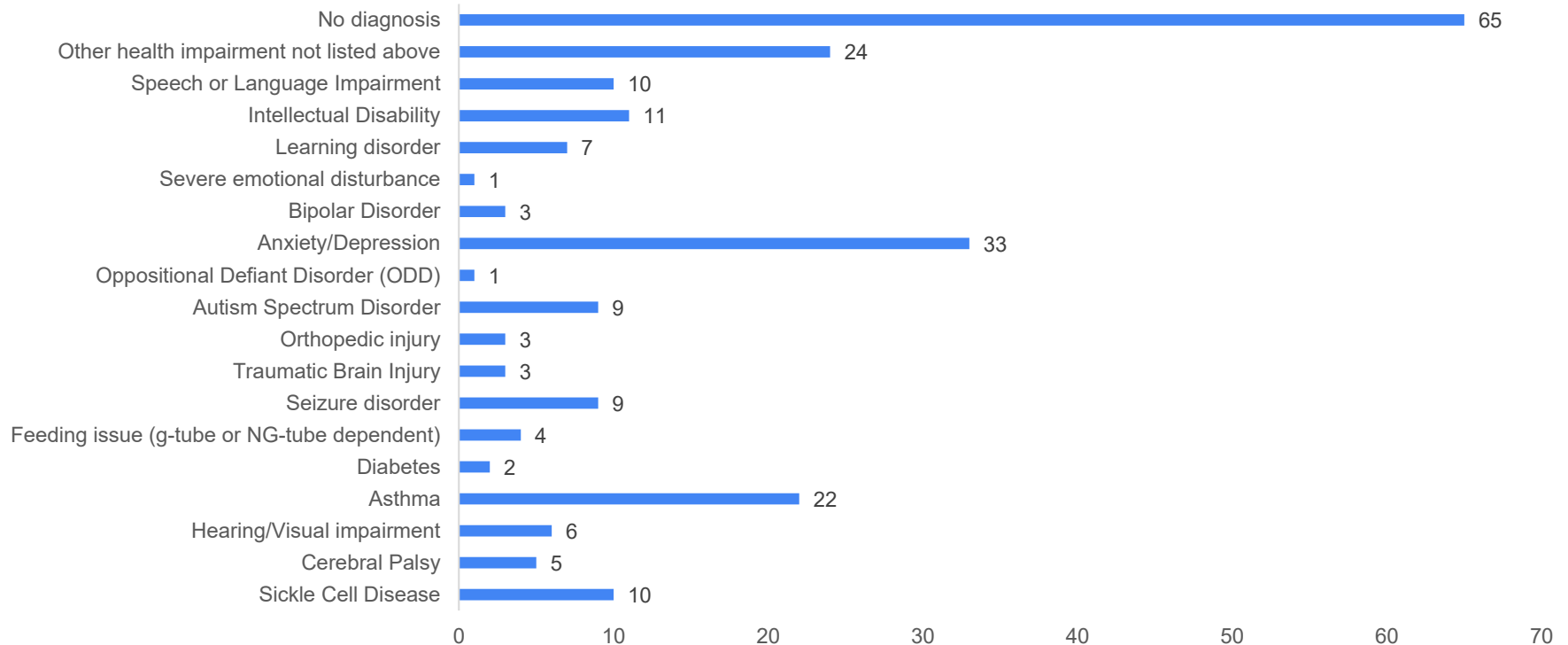
65
respondents
noted **no
diagnosis**

21.7% of all youth represented noted having anxiety or depression

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

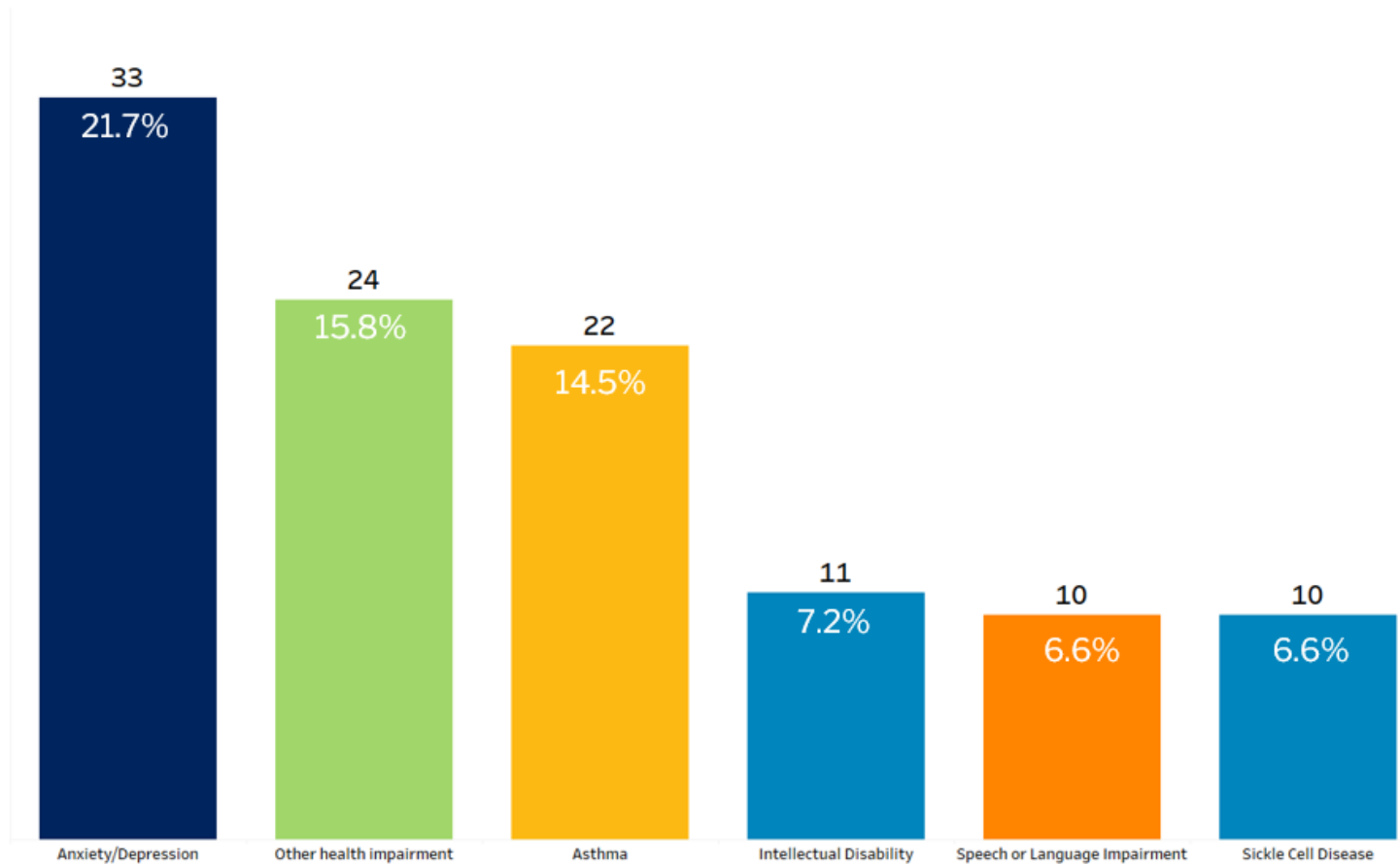
The second most common diagnosis was “**other health impairment**”

Overview of Diagnoses*



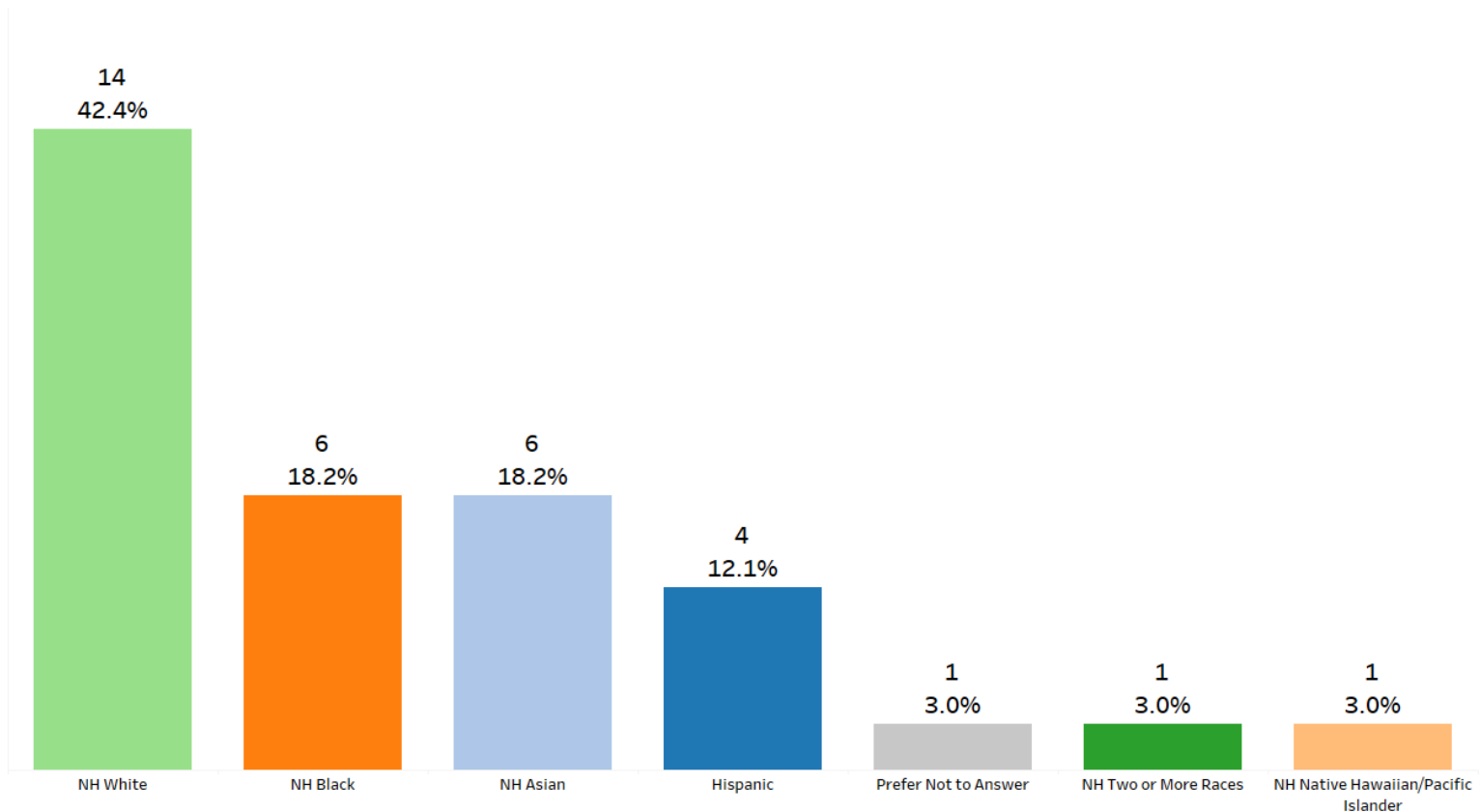
*This does not reflect the number of respondents with diagnoses; 65 respondents reported "no diagnosis" while other respondents had more than one diagnosis.

Top 5 Diagnoses Among Respondents

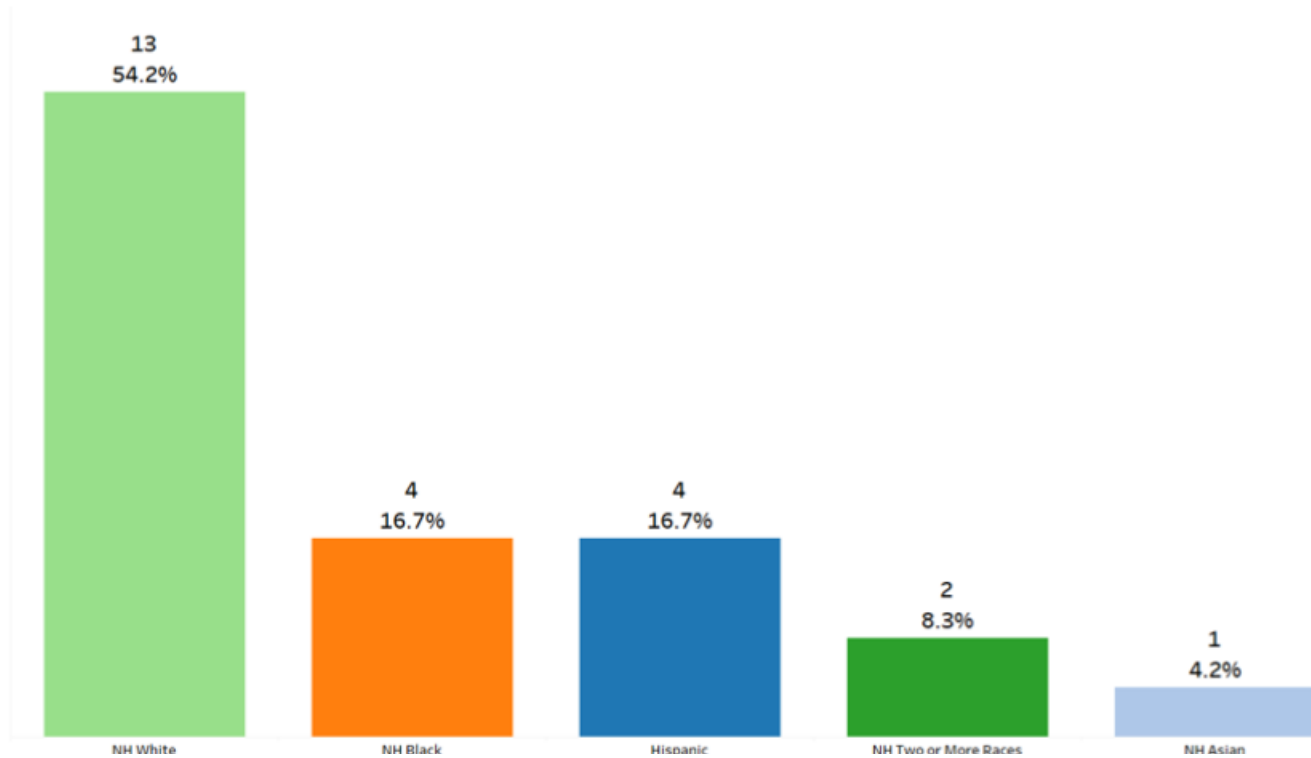


Top 5 Diagnoses by Race and Ethnicity

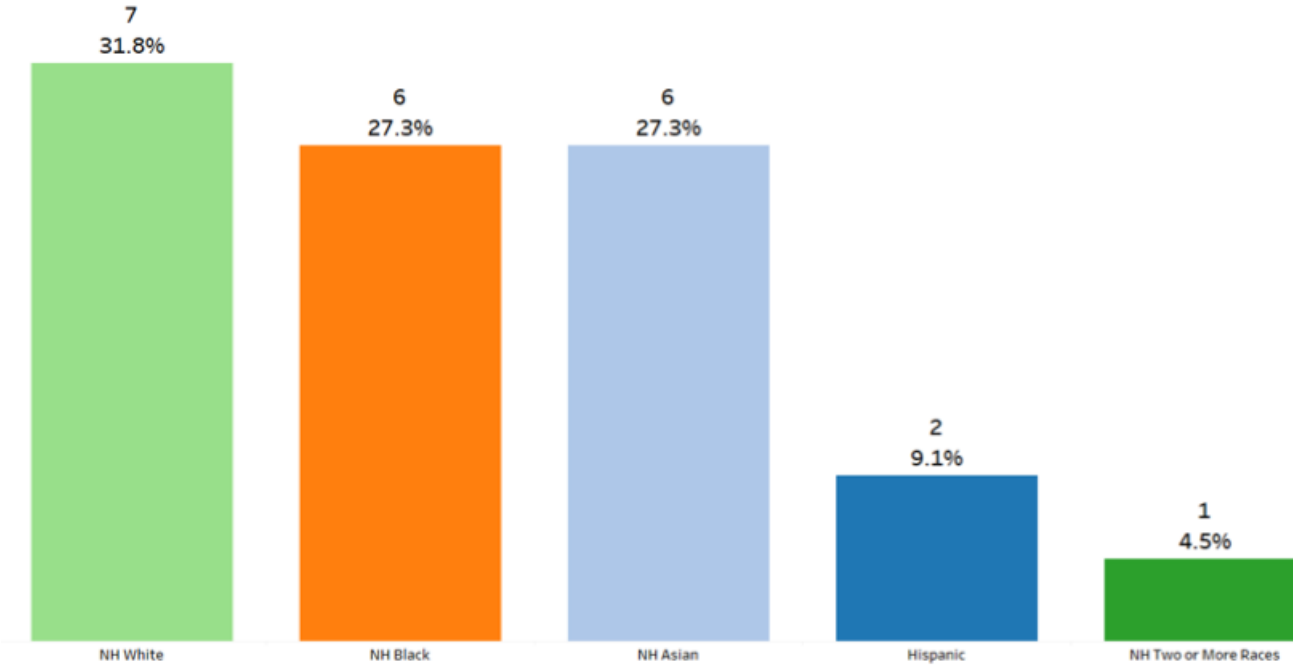
Race and Ethnicity of Youth Represented with Anxiety/Depression and Percent of Total With This Diagnosis



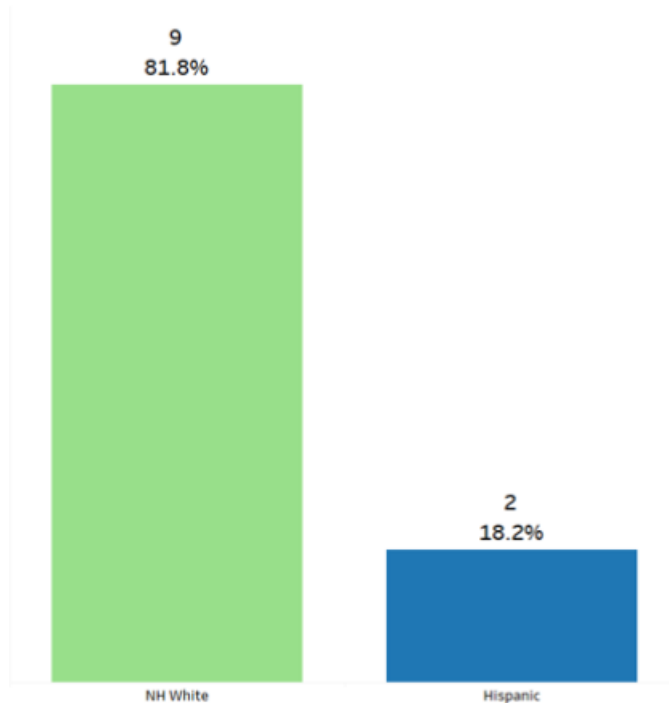
Race and Ethnicity of Youth Represented with “Other Health Impairment” and Percent of Total With This Diagnosis



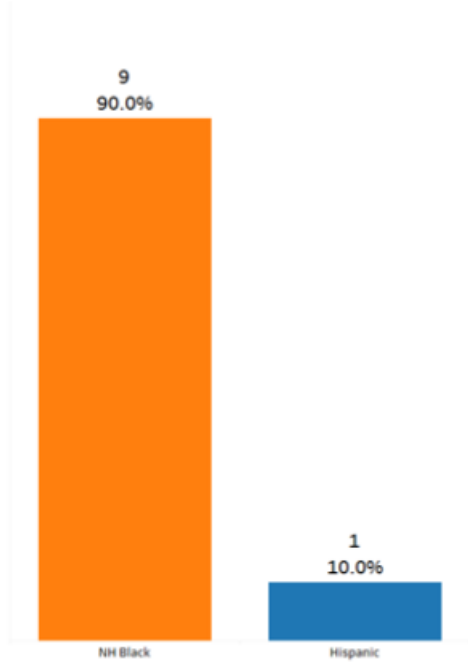
Race and Ethnicity of Youth Represented with Asthma and Percent of Total With This Diagnosis



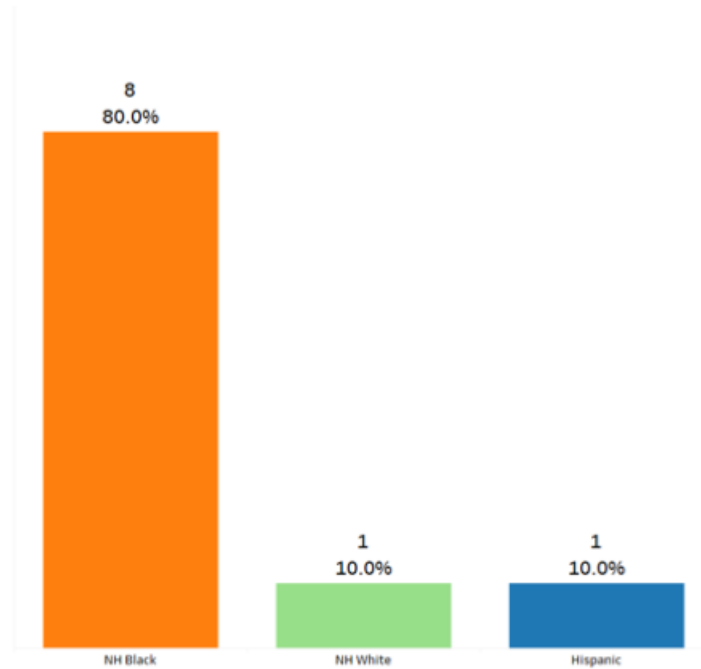
Race and Ethnicity of Youth Represented with Intellectual Disability and Percent of Total With This Diagnosis



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



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

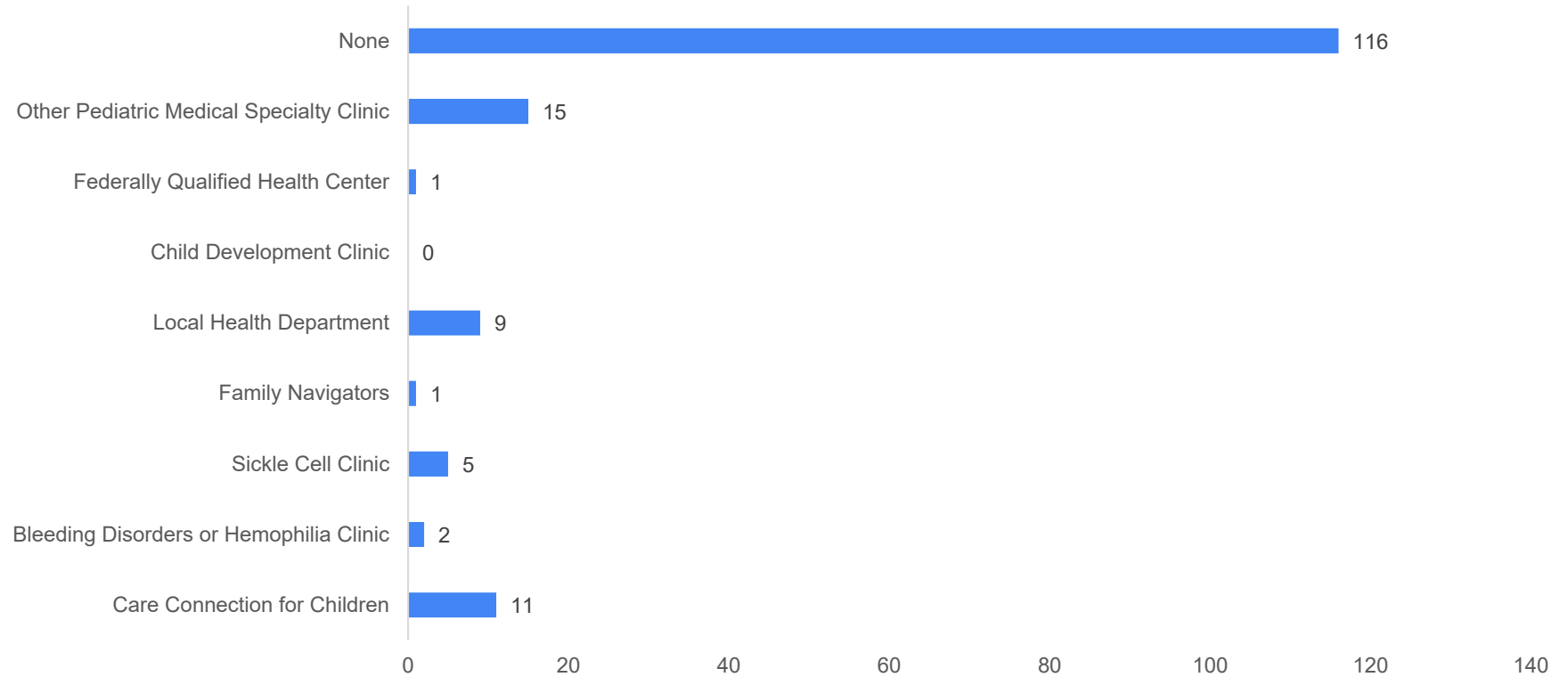


Services Received

37 youth
represented
received a total of
44 different
services

163 diagnoses
reported among **66**
youth represented

Services Received by Youth Represented



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

54.5% of all youth represented with anxiety/depression did not receive services

58% of youth represented with “**other medical diagnosis**” did not receive services

68% of youth represented with **asthma** did not receive services

20.5% of youth represented with a diagnosis received help from a local health department

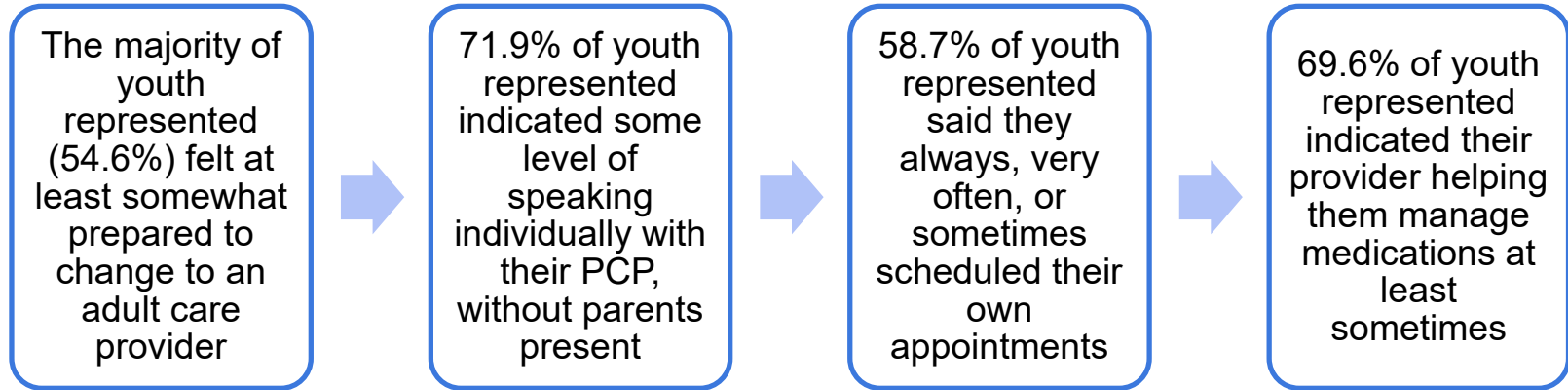
Primary Care Providers

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

Perceptions of Primary Care



“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

“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

Under age 18:
26% knew how they would be insured

Over age 18:
51.9% knew how they would be insured

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

Fear caused people to avoid seeing the doctor

Switch to telehealth viewed as both positive and negative

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