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The Title V Five-Year Needs and Capacity Assessment – Overview

Introduction: Supporting Family Health through the Title V Block Grant

About the Title V Block Grant

The Maternal and Child Health (MCH) Services Title V Block Grant program acts as a safety-net provider for health care and essential public health services for women, mothers, infants, children up to age 22, and children with special health care needs and their families. The program was created as part of the 1935 Social Security Act as a commitment to improving the health and well-being of the country's mothers, children, and families. The Health Resources and Services Administration, a federal agency, oversees the Title V Block Grant program at the federal level. The Title V Block Grant is managed in Pennsylvania by the Bureau of Family Health (BFH) in the Pennsylvania Department of Health.

What is the Title V Five-Year Needs and Capacity Assessment?

Every five years, Pennsylvania's MCH Services Title V Block Grant requires that the BFH conduct a state-level, comprehensive assessment of the health status of women, children, adolescents and children and youth with special health care needs in Pennsylvania to identify health priorities and guide state and local public health work. During this assessment, the BFH also evaluates its capacity to serve these populations.

The guiding principle of the 2020 needs assessment is health equity. Health equity is achieved when all people can attain health and wellness. This assessment will aim to identify specific groups that cannot attain health and wellness because they are underserved and/or are more affected by illness, disease or mortality. Factors influencing health such as social, economic or environmental influences or disadvantages will also be considered.

How will the results of this assessment be used?

The results from the assessment will be used to identify seven to 10 specific priorities that can be positively impacted by strategic public health work over the next five years (2021 to 2025). State and local Title V staff will use the selected priorities to focus efforts, align resources and make a positive impact on the health of the MCH populations.

Methods: Assessing Pennsylvania Health Data and Listening to Family Voices

What does the data say? The first step of the needs assessment looked at available health data on families in Pennsylvania to get a sense of their health and wellness. This included describing how health outcomes have improved, declined or remained the same over the past five years. The BFH looked at data for five different populations: women, infants, children, adolescents and children and youth with special health care needs. We then broke that data down to look at health outcomes by race/ethnicity, age, socioeconomic status, sex, gender identity and sexual orientation, since we know that certain populations experience health problems and illness more often than others due to social and environmental factors.

What are families experiencing? In addition to analyzing existing health data on maternal and child health populations, getting input from families throughout Pennsylvania was an important part of the assessment. The BFH requested input from Title V service recipients and providers about their experiences with the care system and factors influencing their health through a web survey and in-person focus groups.

What is the purpose of this report?

This report will summarize the results from the analysis of available health data as well as the feedback received from families, service recipients and providers over the course of the needs assessment. This data is important because it characterizes the health status of women, infants, children, adolescents and children and youth with special health care needs in Pennsylvania.

The BFH and stakeholders will use this data to inform the selection of the <u>seven to 10 specific priority health needs</u> that will be addressed by the Title V program over the next five years.

Women, Pregnant Women and Mothers

This data brief discusses the health status of women and mothers in Pennsylvania. This includes women, pregnant women and women who have recently given birth and are in the postpartum period – the period within 60 days of delivery.

HEALTH OF **WOMEN AND MOTHERS**

- IMPROVEMENTS & PROGRESS -

- **Well Woman Visit**

  The percentage of PA women aged 18-45 who had a well woman visit increased from 57.9% in 2011 to 61% in 2017, but differences in care exist by education and race/ethnicity. An annual visit with a doctor is recommended for all women so that services like screening, counseling and immunizations can be provided (BRFSS 2011-2017).

- **Discussion of Pre-Conception Health**

  As of 2015, approximately two out of every 10 women in PA (23.5%) delivering a live birth reported having a discussion with a health professional about important health behaviors prior to pregnancy, a 4.0% increase from 2014 but still below the 2020 goal of 27.0%. Women aged 19 and younger, and unmarried women, were less likely to have had a discussion with a provider about their health prior to pregnancy as compared to older and married women (PRAMS 2012-2015).

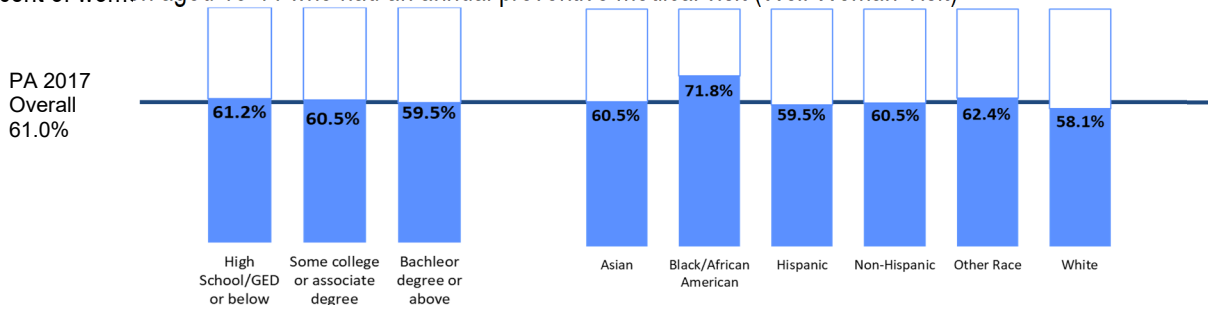
- **Multivitamin use**

  Taking a multivitamin or folic-acid containing vitamin prior to pregnancy is associated with improved health outcomes for mother and infant. Five out of every 10 women in PA delivering a live birth took a multivitamin as of 2015 (49.6%), an increase from 2014 (43%). Yet, multivitamin use was lowest from 2012-2015 among women with a household annual income of $15,000 or less as compared to women with a higher income, women aged 19 years old or younger as compared to older women and women who were Black/African American or Hispanic/Latinx as compared to women of other race/ethnicity (PRAMS 2012-2015).

Preventive Medical Visit

PA Behavioral Risk Factor Surveillance System (BRFSS) • 2011-2017

Percent of women aged 18-44 who had an annual preventive medical visit (Well Woman Visit)



by Education

**Total women surveyed: 20,123*

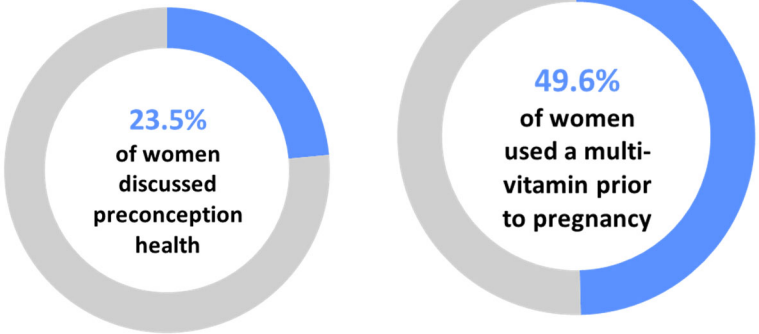
by Race/Ethnicity

**Total women surveyed: 19,695*

Pre-conception Health Behaviors

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2015

Percent of women who reported positive health behaviors prior to pregnancy



**Total women surveyed: 1,094*

**Total women surveyed: 1,094*

**Total women surveyed: 1,041*

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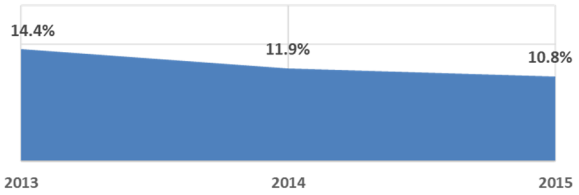
TITLE V FIVE-YEAR NEEDS AND CAPACITY ASSESSMENT: DATA BRIEFS

Smoking During Pregnancy

The percentage of women who reported smoking during the last trimester of pregnancy decreased from 14.4% in 2013 to 10.8% in 2015. From 2012-2015, smoking was more commonly reported among pregnant women aged 19 or younger (16.6%) as compared to older women (7.5%), and among women with a high school education or less (20.3%) (PRAMS 2012-2015).

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2013- 2015

Percent of women smoking during the 3rd trimester



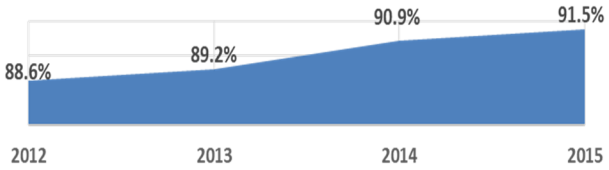
Total women surveyed: 3,260

Postpartum Care and Birth Control

The percentage of women in PA who attend a medical visit after birth has consistently increased from 88.6% in 2012 to 91.5% in 2015, exceeding the 2020 goal of 90.8%. Using contraception after birth helps new mothers prevent unintended pregnancy. Although the percentage of women who report using contraception after birth has decreased from 80% in 2012 to 75.1% in 2015, PA still exceeds the 2020 goal of 58.5% of women using contraception after birth (PRAMS 2012-2015).

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012- 2015

Percent of women who received postpartum care



By Year

Total women surveyed: 4,057

-ONGOING HEALTH ISSUES & DISPARITIES-

Maternal mortality

Pregnancy-related deaths occur during pregnancy or within one year of its end. In PA, the rate was 13.3 pregnancy-related deaths per 100,000 live births during 2011-2015. This exceeds the 2020 goal of 11.4 pregnancy-related deaths per 100,000 live births and racial disparities still exist (Pregnancy Mortality Surveillance System, 2009-2015).

Black/African American women in PA are 3 times more likely to die a pregnancy-related death than White women

Early and Adequate Prenatal Care

Health care during pregnancy is important for the health of both mother and child. In PA 1.6% of all women with a live birth have had no prenatal care from 2015 to 2017 and about three out of every 10 women in PA (26.2%) have not had timely prenatal care starting in the first trimester. As of 2016, 73.8% of women in PA received prenatal care starting in the first trimester (below the 2020 goal of 77.9%) and differences exist by race/ethnicity. Black/African American mothers were least likely to receive prenatal care as compared to women of other race/ethnicity (PA Birth Certificate Data 2012-2017).

Black/African American women in PA are three times as likely to receive no prenatal care than White women

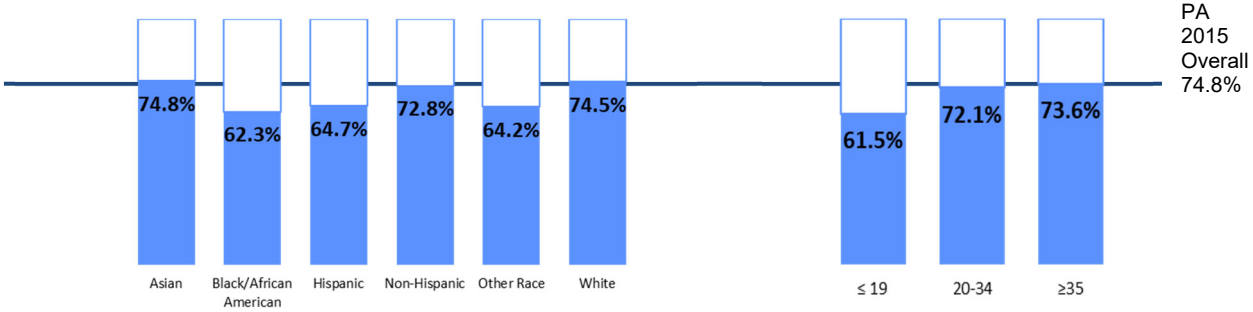
In PA ~3 of every 10 women receives late prenatal care

Prenatal care is adequate if started early and the number of visits is consistent with doctors' recommendations. In PA, the percentage of women receiving adequate prenatal care increased from 69.1% in 2013 to 74.8% in 2015. However, differences persist by race/ethnicity, income, education and maternal age (PRAMS 2012-2015).

Adequate Health Care During Pregnancy

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012-2015

Percent of women who received adequate prenatal care



by Race/Ethnicity

Total women surveyed: 2,821

by Maternal Age

Total women surveyed: 2,868

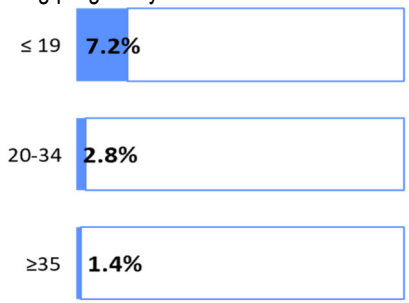
TITLE V FIVE-YEAR NEEDS AND CAPACITY ASSESSMENT: DATA BRIEFS

Intimate Partner Violence During Pregnancy

The percentage of PA women who reported experiencing intimate partner violence during pregnancy has decreased from 4.6% in 2012 to 2.1% in 2015. However, women aged 19 or younger, Black/African American women, and women with a household income of $15,000 or less most frequently reported physical abuse, receiving verbal threats, feeling frightened for their safety or feeling controlled by their partner during pregnancy (PRAMS 2012-2015).

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012-2015

Percent of women who reported intimate partner violence during pregnancy



by Maternal Age

**Total women surveyed: 4,055*

Gestational Diabetes and Hypertension

As of 2017, 5.8% of women in PA had gestational diabetes and women aged 35 and older were more likely to have it (9.0%) as compared to younger women (2.0%). Asian/Pacific Islander women were also more likely to have gestational diabetes (10%) as compared to women of other races (4.2%). In 2017, 6.2% of women in PA reported having gestational hypertension and it was more frequent among mothers aged 19 and younger (7.5%) as compared to older mothers (6.0%) and among Black/African American mothers (8.9%) compared to women of other races (3.7%) (PA Birth Certificate Data, 2017).

Pre-Pregnancy Weight

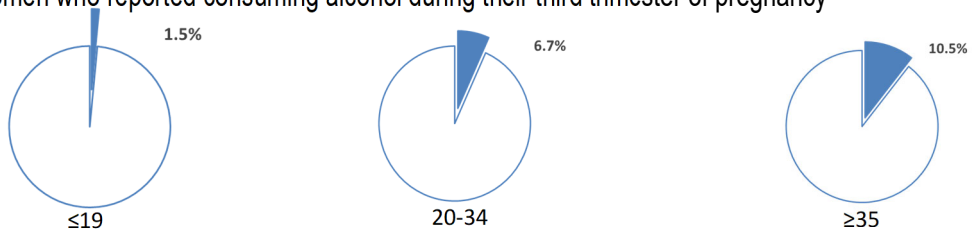
Maintaining a healthy pre-pregnancy weight can reduce the risk of complications during pregnancy. The percentage of women with a healthy weight prior to pregnancy decreased from 51.4% in 2013 to 48.0% in 2015. During 2012-2015 Black/African American women were least likely to report a healthy pre-pregnancy weight (33.0%) as compared to women of other races. Asian women (63.7%) were most likely to report a healthy weight as compared to women of other race/ethnicity (PRAMS 2012-2015).

Alcohol Use During Final Three Months of Pregnancy

The percentage of women who reported consuming alcohol within the last trimester of pregnancy has increased from 6.1% in 2012 to 8.0% in 2015. Alcohol consumption was most common among mothers over the age of 35 (10.5%) as compared to younger women and among mothers with a bachelor's degree or higher (10.5%) as compared to women with a high school education (4.6%) (PRAMS 2012-2015).

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012-2015

Percent of women who reported consuming alcohol during their third trimester of pregnancy



by Maternal Age

**Total women surveyed:4,033*

- MINIMAL CHANGE -

Pregnancy Weight Gain

The percentage of women in PA giving birth to one child who reported gaining more than recommended during pregnancy was consistent from 2012-2015 (from 55.0% in 2012 to 54.3% in 2015). While gaining too little can impact the development of the infant, too much may cause health problems after pregnancy (PRAMS 2012-2015).

Antepartum depression

The percentage of PA women told they had depression during pregnancy was consistent from 2013 to 2015; there was a slight decrease from 10.1% in 2013 to 9.8% in 2015 (PRAMS 2012-2015).

Dental Care During Pregnancy

The percentage of women who reported having a preventive dental visit during pregnancy was consistent from 2012-2015 with 54.6% of women having a dental visit in 2012 and 54.7% in 2015 (PRAMS 2012-2015).

C-Section

Women giving birth to their first child with no known complications are considered low-risk and, in such cases, a c-section may pose increased risk unnecessarily. As of 2017, 25.2% of PA women considered low risk had a c-section. Reducing the percentage of medically unnecessary c-section deliveries among low risk first births is recommended for improving health outcomes and quality of care. (PA Birth Certificate Data 2017).

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Infants

This data brief discusses the health status of infants in Pennsylvania. Infants are children in their first year of life – within 365 days of birth.

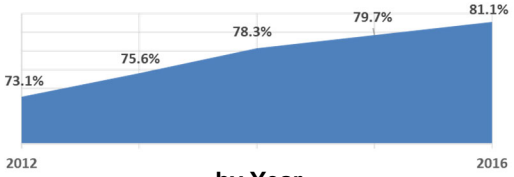
HEALTH OF **INFANTS**

- IMPROVEMENTS & DISPARITIES –

Breastfeeding

The percentage of infants ever breastfed has increased from 73.1% in 2012 to 81.1% in 2016 but is still below the 2020 goal of 81.9% overall and in 41 of the 67 counties.

PA Birth Certificate Dataset • 2012-2016
Percent of infants ever breastfed

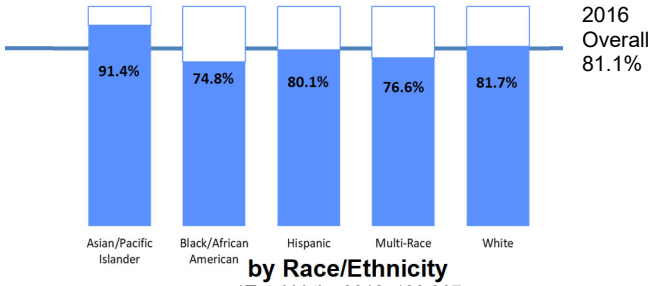


by Year

**Total births 2012-2016: 678,922*

Black/African American and multi-race infants were least likely to be breastfed as compared to infants of other race/ethnicity, as were infants born to mothers less than age 24 or older than age 45 when compared to infants born to mothers of other ages. Infants born in rural counties were also less likely to be breastfed (PA Birth Certificate Dataset, 2012-2016).

PA Birth Certificate Dataset • 2012-2016
Percent of infants ever breastfed



by Race/Ethnicity

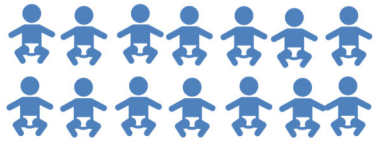
**Total births 2016: 133,907*

Infant Mortality

The infant mortality rate in PA has decreased from 7.0 deaths per 1,000 live births in 2012 to 6.1 deaths per 1,000 live births in 2016 – nearly meeting the 2020 goal of 6.0 deaths. Yet, the infant mortality rate for Black/African American infants is 14.6 deaths per 1,000 live births – two times higher than the overall state rate, six times higher than the mortality rate for Asian/Pacific Islander infants (2.3) and three times higher than the rate for White infants (4.6) (PA Death Certificate Dataset, 2012-2016).

For every 1,000 live births in PA in 2016,
4.6 White infants died

For every 1,000 live births in PA in 2016,
14.6 Black infants died



Pre-term Related Mortality

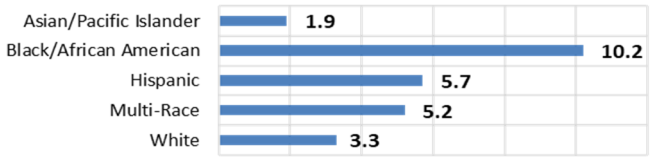
Pre-term related death is the leading cause of infant death in PA. The pre-term related mortality rate decreased from 2.8 deaths per 1,000 live births in 2012 to 2.4 deaths per 1,000 live births in 2014. In 2015, the rate increased slightly to 2.5 deaths per 1,000 live births. Infants born to mothers aged 15-19 had a higher risk of mortality in 2016 as compared to infants born to mothers of other ages as did infants born to Black/African American mothers compared to infants born to mothers of other race/ethnicity (NVSS 2012-2015; CDC Wonder 2016).

Neonatal mortality

Neonatal deaths occur within the first month of an infant's life. The neonatal mortality rate in PA decreased from 5 deaths per 1,000 in 2012 to 4.4 deaths per 1,000 live births in 2016. Yet, neonatal death rates are higher among Black/African American, Hispanic and multi-race infants as compared to White and Asian/Pacific Islander infants (PA Death Certificate Dataset 2012-2016).

Black/African American infants are 3 times as likely to die before their first birthday than White infants in PA

PA Death Certificate Dataset • 2012-2016
Neonatal mortality rate per 1,000 live births



by Race/Ethnicity

Number of deaths per 1,000 live births

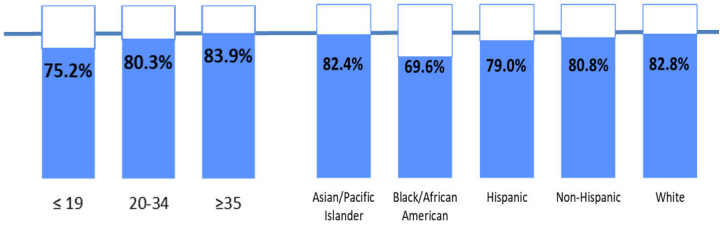
Post neonatal mortality

Post neonatal mortality rates include deaths that occur when an infant is between 1 month and 1 year old. The post neonatal mortality rate in PA has decreased from 2 deaths per 1,000 live births in 2012 to 1.7 deaths per 1,000 live births in 2016. However, the disparities by race/ethnicity persist as the post neonatal mortality rate was three times higher among Black/African American infants (4.3) and multi-race infants (3.6) as compared to White infants (1.3) in 2016 (PA Death Certificate Dataset 2012-2016).

Infant sleep position, practices and sleep-related death

The percentage of mothers who report placing their infants on their backs to sleep increased from 76.7% in 2014 to 84% in 2015. Although this percentage exceeds the national average, mothers younger than 19 were least likely to place their infant to sleep on their backs as compared to mothers of other ages. African American/Black mothers were also less likely to report placing their infant to sleep on their back as compared to mothers of another race/ethnicity.

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012-2015
Percent of mothers who reported placing infant to sleep on their back



by Maternal Age
**Total women surveyed: 3,835*

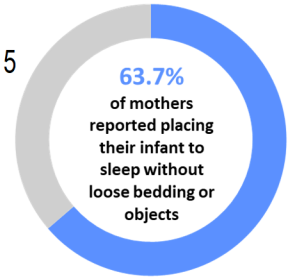
by Race/Ethnicity
**Total women surveyed: 3,905*

PA 2015 Overall 84%

From 2012 to 2015, the percentage of mothers placing their infants on a separate sleep surface reached a four-year low in 2015 (49.2%) as did the percentage of mothers placing their infant on a separate, firm sleep surface such as a crib (40.3%). The percentage of infants placed to sleep without loose bedding increased from 51.6% in 2012 to 63.7% in 2015 (PA PRAMS, 2012-2015).

PA Pregnancy Risk Assessment Monitoring System (PRAMS) • 2012-2015
Percent of mothers who reported placing their infant to sleep on a separate surface

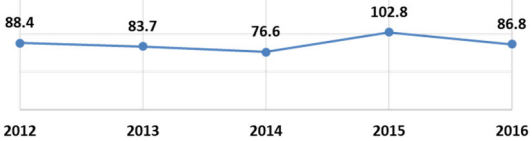
by Year
**Total women surveyed: 3,937*



**Total women surveyed: 3,871*

The rate of sleep-related sudden unexpected infant death was 88.4 deaths per 100,000 in 2012, spiked to 102.8 deaths per 100,000 live births in 2015 and then decreased to 86.6 in 2016.

PA National Vital Statistics System (NVSS) • 2012-2015
Rate of sleep-related sudden unexpected infant death per 100,000 live births



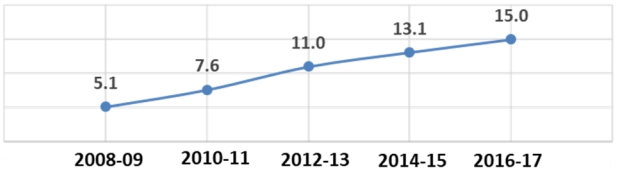
by Year
Number of sleep-related deaths per 100,000 live births

- ONGOING HEALTH ISSUES & DISPARITIES-

Neonatal Abstinence Syndrome

Neonatal abstinence syndrome (NAS) describes health problems that result from an infant withdrawing from addictive drugs to which he or she was exposed while in the womb. Since 2008-2009, the rate of infants born with NAS has steadily increased, reaching a rate of 15 infants born with NAS per 1,000 hospital births in 2015-2016, nearly triple the state rate 2008-2009, which was 5.1. In 2015-2016, rates of NAS were highest among white infants and those born into a household with a median household annual income below $80,000.

PA Health Care Cost Containment Council • 2008-2017
Rate of infants born with NAS per 1,000 hospital births (two-year estimates)



by Year
Number of infants born with NAS per 1,000 hospital births

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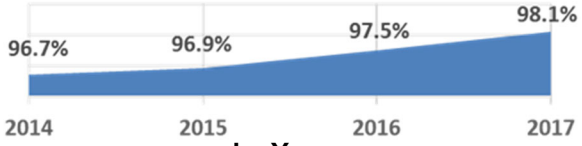
Newborn Screening

Infants born in PA receive a dried blood spot (DBS) screen, a hearing screen and a critical congenital heart defects screen to identify conditions that can cause serious illness or death if untreated. The percentage of infants born in PA who received a hearing screening before one month of age has increased from 96.7% in 2014 to 98.1% in 2017.

PA Newborn Screening Database • 2014-2017
% of infants born in PA with a hearing screen before 1 month of age

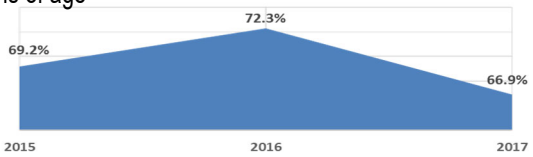


by Year

**Total diagnosed 2015-2017: 2,143*

However, PA has seen a decline in the number of newborns who received a diagnosis of abnormal hearing by three months of age, from 69.2% in 2015 to 66.9% in 2017.

PA Newborn Screening Database • 2015-2017
Percent of infants born in PA diagnosed with hearing loss before 3 months of age

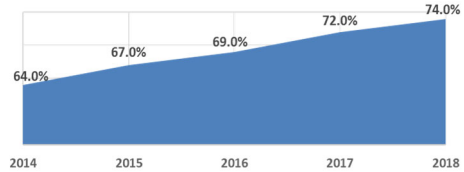


by Year

In 2018, 99.5 % of the newborns that received a PA birth certificate, received a blood spot screen. There were 1,055 screens with an abnormal result. Of those, 70.4% were reported out by the lab within the recommended time period: five days for conditions that present within the first week, seven days for conditions that symptoms show up after that time, 29.6% below the 2020 goal of 100%.

Timeliness in report out of blood spot screening results depends on both timely collection and receipt of the blood spot screening at the lab. The time from collection of the blood spot screening to receipt at the lab should occur within 48 hours (two days). In 2018, only 74% of blood spot screens reached the lab within two days after collection. This has increased from 64% in 2014, however, this timeframe leaves the lab only one day to test and report results to the hospital, when newborn symptoms show up in less than five days. It is important that the lab receives blood spot screens within two days to ensure timely identification of infants in need of treatment or other services (Newborn Screening Database, 2014-2018).

PA Newborn Screening Database • 2014-2018
% of newborn specimens collected and received at the lab within 48 hours

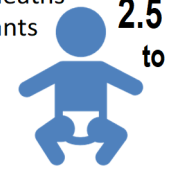


by Year

**Total occurrent births 2014-2016: 557,163*

Sudden Unexpected Infant Death (SUID)

Sudden unexpected infant death (SUID) is the death of an infant less than one year old that occurs suddenly and unexpectedly. As of 2015, there were 102.8 SUID deaths in PA per 100,000 live births, higher than the 2020 goal of 84 SUID deaths per 100,000. When stratified by race/ethnicity, Black/African American infants are 2.5 times more likely to die of SUID than White infants in PA (NVSS 2015; CDC Wonder, 2012-2015).



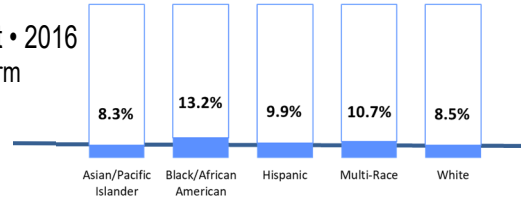
Black/African American infants are 2.5 times as likely to die of SUID than White infants in PA

- MINIMAL CHANGE -

Pre-term birth

Babies born preterm (less than 37 weeks) are at greater risk of health problems and complications. The percent of preterm births in PA has remained constant around 9.4% from 2012 to 2016, meeting the 2020 goal of 9.4%. As of 2016, women under the age of 17 or over the age of 35 were more likely to give birth pre-term as compared to women of other ages, as were Black/African American and multi-race women as compared to women of another race/ethnicity (PA Birth Certificate Dataset, 2012-2016).

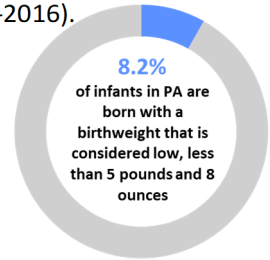
PA Birth Certificate Dataset • 2016
Percent of infants born pre-term



PA 2016 Overall 9.3%

by Maternal Race/Ethnicity

**Total births: 139,356*



**Total live births: 139,356*

Low birthweight delivery

In PA, the percentage of low birthweight deliveries (less than 2,500 grams) has remained around 8.2% from 2012 to 2016. Similarly, the percentage of very low birthweight births (less than 1,500 grams) has remained nearly unchanged from 2012 to 2016 and is at 1.5% as of 2016 (PA Birth Certificate Dataset 2012-2016).

HEALTH OF **CHILDREN**

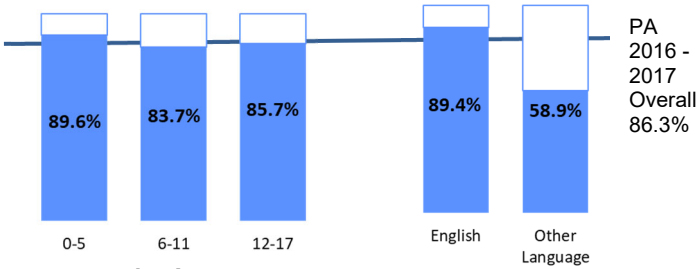
Children
This data brief discusses the health status of children in Pennsylvania. This includes children between the ages of 1 and 21.

- IMPROVEMENTS & PROGRESS –

Child Well Visit

Preventive medical visits are important for children in order to monitor growth and development. As of 2016-17, 86.3% of children aged 0-17 in PA had a well visit within the last year, higher than the national average of 82.0%. Visits were most common among children aged 0-5 (89.6%) and less common among older children. Additionally, children speaking a language other than English were less likely to have had a child well visit (NSCH 2016-17).

National Survey of Children's Health (NSCH) • 2016-2017
Percent of children with a preventive visit during the last year



by Age
**Total surveyed:1,514*

by Language Spoken
**Total surveyed: 1,508*

As of 2016-17, 73.5% of parents report always receiving specific, needed information about their child's health from a doctor or health care provider, exceeding the 2020 goal of 52.8% (NSCH 2016-2017).

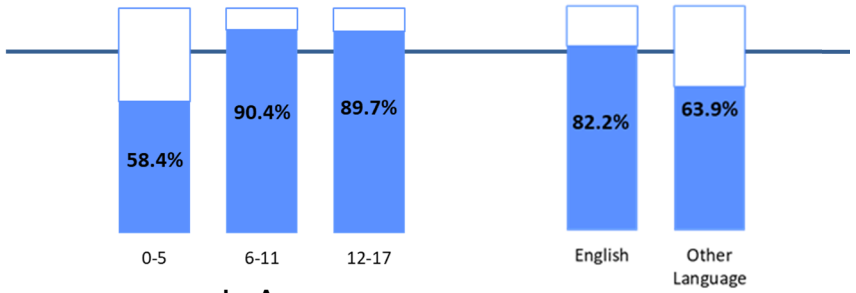
Mental/Behavioral Health Treatment

Early identification and treatment of mental or behavioral health issues is important to a child's overall health. In 2016-2017, 11.8% of children aged 3-17 in PA received treatment or counseling from a mental health care professional. Although 1.2% of children aged 3-17 reported not receiving needed mental health, this is lower than the national percentage of 2.4% (NSCH 2016-2017).

Preventive Dental Visit

As of 2016-2017, 80.5% of children aged 1-17 in PA reported seeing an oral health care provider for preventive care via the NSCH, which exceeds the national average of 79.5%. However, children aged 1-5 were less likely to have had a preventive dental visit compared to older children, as were children who spoke a language other than English (NSCH 2016-2017).

National Survey of Children's Health (NSCH) • 2016-2017
Percent of children with a preventive dental visit within the last year

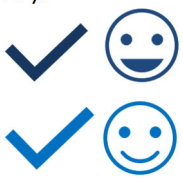


by Age
**Total surveyed:1,454*

by Language Spoken
**Total surveyed: 1,449*

Parent-Reported Health Status

As of 2016-2017, 92.3% of children in PA aged 0-17 were reported by their parents to have excellent or very good health compared to only 89.8% of children nationally. Although PA exceeds the national average, some disparities do exist as Hispanic children were less likely to be reported as having very good or excellent health compared to children of other ethnicity, as were children who speak a language other than English (NSCH 2016-2017).



92.3% of children aged 0 to 17 in PA were reported by their parent or guardian to be in excellent or very good health

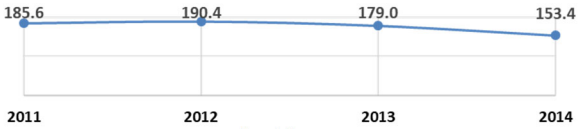
Bullying

As of 2016-17 19.0% of children aged 6-17 were reported as having experienced bullying in PA, a percentage that is slightly below the national average of 21.7%. In PA, bullying was more common among 12-17 year old's (20.9%) than among 6-11 year old's (17.2%) (NSCH 2016-2017).

Non-fatal Injury Hospitalizations

Non-fatal injuries which require hospitalization can develop into long-term health issues. In PA the rate of hospitalization for non-fatal injury has decreased from 185.6 hospitalizations per 100,000 children aged 0-9 in 2011 to 153.4 hospitalizations per 100,000 children in 2014. However, the PA rate is slightly higher than the national average of 146 hospitalizations per 100,000 children (HCUP 2011-2014).

PA Health Care Cost & Utilization Project• 2011-2014
Rate of non-fatal injury hospitalization per 100,000 children aged 0-9



by Year

Number of children hospitalized for non-fatal injury per 100,000 children between the ages of 0 and 9

Child Mortality

The 2020 goal is to reduce the child mortality rate to 26.5 deaths per 100,000 children aged 1-4 and to 12.4 deaths per 100,000 among children aged 5-9 years. In both age groups PA met this goal from 2012 to 2017. For the 1-4 age group, PA's child mortality rate in 2017 was 19.5 child deaths per 100,000 children. For the 5-9 age group, the child mortality rate in 2017 was 11.7 child deaths per 100,000 children (CDC Wonder 2012-2017).

The leading causes of death among children aged 1-4 in PA as of 2017 are:

1) Birth defects
2) Accidents and unintentional injuries

The leading causes of death among children aged 5-9 in PA as of 2017 are:

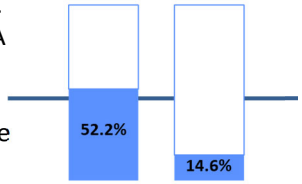
1) Accidents and unintentional injuries
2) Cancer
3) Birth defects

-ONGOING HEALTH ISSUES & DISPARITIES-

Medical Home

A medical home is a team-based healthcare delivery system which aims to provide coordinated and comprehensive care. As of 2016-2017, 48.5% of children under the age of 18 in PA reported receiving care in a medical home while 48.6% of children receive such care nationally – both below the 2020 goal of 63.3%. In PA, children under 18 that spoke a language other than English were least likely to have a medical home (14.6%) as compared to children who spoke English (52.2%) (NSCH 2016-2017).

National Survey of Children's Health • 2016-2017
Percent of children under 18 who received health care in a medical home



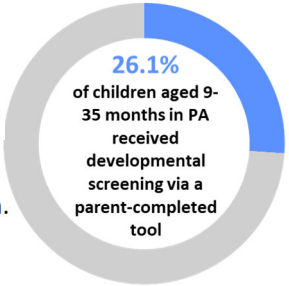
by Language Spoken

**Total surveyed: 871*

PA 2016 -2017
Overall 48.5%

Developmental Screening

Identification of developmental delays via early screening is important for a child's health. In PA only 26.1% of children aged 9-35 months received developmental screening via a parent-completed tool as compared to 31.1% of children who received such screening nationally in 2016-2017 (NSCH 2016-2017).



**Total surveyed: 164*

Immunization

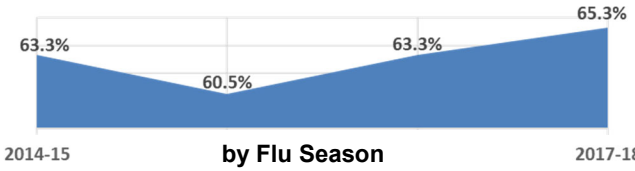
The combined seven-vaccine series aims to induce active immunity against childhood disease including diphtheria, tetanus and pertussis (DTaP), Poliomyelitis (polio), measles, mumps and rubella (MMR), Haemophilus influenza B (HiB), Hepatitis B (HepB), Varicella and Streptococcus pneumoniae (PCV). The percentage of children aged 19-35 months who have received the complete series in PA appears to have decreased from 72.8% in 2015 to 70.4% in 2017. This remains below the 2020 goal of 80% (NIS 2015-2017).

In PA 3 of every 10 children between the ages of 19-35 months in PA have not received the complete seven-vaccine series and are not fully immunized

Seasonal Flu Vaccination

Seasonal flu vaccination among children aged 6 months to 17 years increased in PA to a four-year high of 65.3% in 2017-2018, exceeding the national average of 57.9%. PA has not yet met the 2020 goal of 70.0% influenza vaccine coverage (NIS-Flu, 2014-2018)

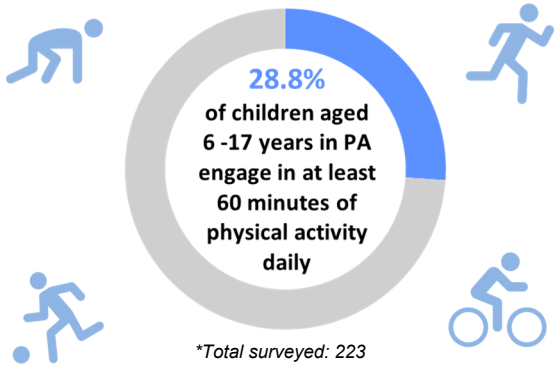
National Immunization Survey - Flu • 2014-2018
Percent of children aged 6 to 17 who received a seasonal flu vaccine



by Flu Season
Total surveyed: 20,051

Physical Activity

Regular physical activity among children can result in increased likelihood of positive health outcomes across the life course. As of 2016-2017, 28.8% of children aged 6-17 years reported engaging in at least 60 minutes of physical activity every day in PA, exceeding the national average of 23.1%. Daily physical activity was more common among children aged 6-11 years old (28.8%) as compared to children aged 12-17 years old (19.8%) (NSCH, 2016-2017).



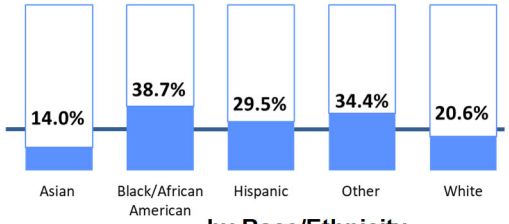
Total surveyed: 223

Adverse Childhood Experiences (ACES)

Adverse childhood experiences (ACES) are events that cause stress or trauma in a child's life and may impact health outcomes and well-being across the life course. The National Survey of Children's Health asks parents whether their child has experienced one of the following ACES:

1) Parent or guardian divorce or separation
2) Death of parent or guardian
3) Jail time for parent or guardian
4) Witnessed/heard violence between parents
5) Victim or witness of neighborhood violence
6) Lived with someone with mental illness
7) Lived with someone with a drug/alcohol problem
8) Unfair treatment because of race/ethnicity
9) Hard to get by on family's income

National Survey of Children's Health • 2016-2017
Percent of children aged 0 to 17 who were reported to have experienced at least one adverse childhood experience (ACE)



PA 2016 -2017
Overall 24.0%

by Race/Ethnicity
Total surveyed: 1,511

As of 2016-2017, 24.0% of children aged 0-17 were reported by their parents to have experienced at least 1 ACE. Disparities exist as ACES were more commonly reported for non-Hispanic Black/African American children as compared to children of another race/ethnicity (NSCH 2016-2017).

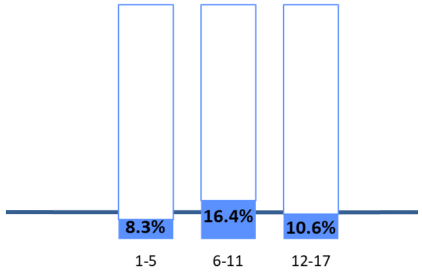
Environmental Tobacco Smoke (ETS)

According to 2016-2017 data, 19.2% of children aged 0-17 in PA were living in a household with someone who smoked whereas 15.5% of children were living in such a household nationally (NSCH 2016-2017).

Tooth Decay

Tooth decay is a preventable condition that is common among children. As of 2016-2017, 12.0% of children aged 0-17 in PA reported having had tooth decay or a cavity in the past year – a percentage that is only slightly above the national average of 11.7%. Tooth decay was more common among 6-11 year old's as compared to children of other ages (NSCH 2016-2017).

National Survey of Children's Health • 2016-2017
% of children aged 1 to 17 who had decayed teeth or cavities within the past year



PA 2016 -2017
Overall 12.0%

by Age
Total surveyed: 132

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HEALTH OF **ADOLESCENTS**

Adolescents

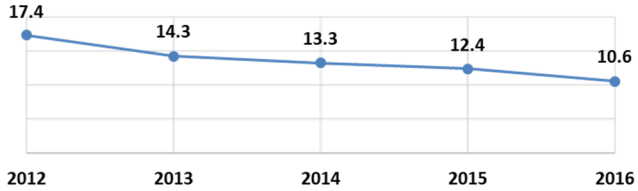
Adolescence is the period of growth and development between childhood and adulthood. This data brief discusses the health status of adolescents in Pennsylvania. Adolescents are youth between the ages of 12 and 21.

- IMPROVEMENTS & PROGRESS –

Adolescent Pregnancy

The pregnancy rate among adolescents aged 15 to 17 years in PA consistently decreased from 17.4 pregnancies per 1,000 females in 2012 to 10.6 pregnancies per 1,000 females in 2016, which is well below the 2020 goal of 36.2. Although the adolescent pregnancy rates differ by race/ethnicity, ranging from 2.8 (Asian/Pacific Islander) to a high of 25.4 (Black/African American), all rates are still below the 2020 goal (EDDIE 2012-2016).

PA Birth Certificate Dataset • 2012-2016
Rate of pregnancies among adolescents aged 15 to 17 per 1,000 women



by Year

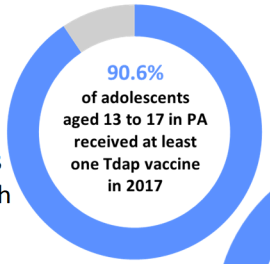
Number of adolescent pregnancies per 1,000 women

Transition to Adult Care

The transition from pediatric to adult-oriented healthcare often involves various steps including transferring records and insurance information. As of 2016-2017, 16.2% of adolescents (aged 12-17) reported receiving the services necessary to make the transition to adult health care, above the national average of 14.6% (NSCH 2016-2017).

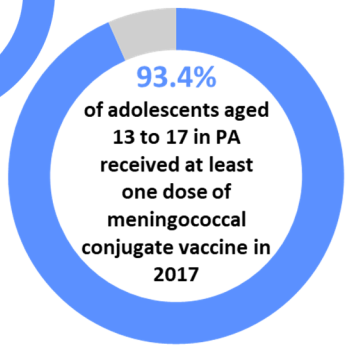
Immunization – Tdap and MCV

The Tdap vaccine is given as a booster immunization to adolescents to provide continued protection against tetanus, diphtheria and pertussis. In 2017, 90.6% of adolescents ages 13 to 17 in PA received at least one dose of the Tdap vaccine which exceeds the 2020 goal of 80.0% (NIS-Teen, 2015-2017).



**Total surveyed: 851, results are weighted to be representative of all 13 to 17 year old's in PA*

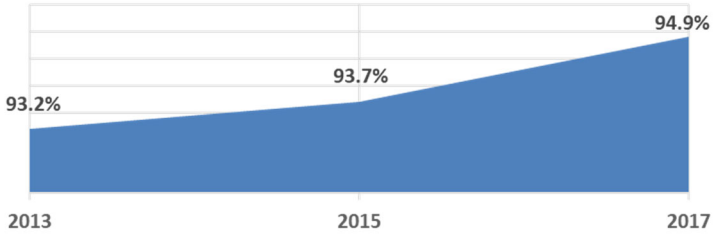
Routine meningococcal conjugate vaccination (MCV) is recommended for preteens and teens aged 11 to 12 years old with a booster for adolescents at 16 years of age. In 2017, 93.4% of adolescents ages 13 to 17 in PA received at least one dose of the MCV which exceeded the 2020 goal (80.0%) as well as the 2017 national average of 85.1% (NIS-Teen, 2015-2017).



Inappropriate Use of Prescription Drugs

As inappropriate use of prescription medication is a contributor in the growing opioid epidemic, it is important to understand these trends in the adolescent population. While the trend is small, it appears that the percentage of adolescents who responded that they have not used prescription pain relievers (0 occasions of use) has slightly increased from 2013 to 2017 (PAYS 2013-2017).

Pennsylvania Youth Survey• 2013, 2015, 2017
Percent of adolescents who report never using prescription drugs without a doctor's orders



by Year

**No raw counts were available; Data was only available as percentages*

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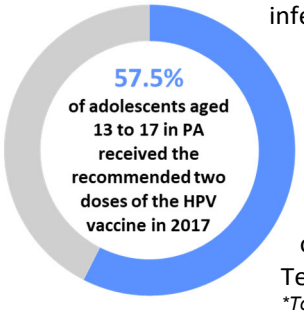
Non-fatal Injury Hospitalization

Non-fatal injury hospitalization rates among adolescents aged 10-19 in PA decreased from 388.8 hospitalizations per 100,000 adolescents in 2011 to 311.1 in 2014. Data from 2017 indicate that the adolescent non-fatal injury hospitalization rate may be as low as 255.1 hospitalizations per 100,000 adolescents (PHC4 2011-2017).

-ONGOING HEALTH ISSUES & DISPARITIES-

Immunization – HPV

The human papillomavirus (HPV) vaccine protects against cancers caused by HPV infection. Two doses of HPV vaccine are recommended to provide protection. Only 57.5% of PA adolescents aged 13-17 reported receiving at least two doses of HPV in 2017, falling short of the 2020 goal of 80.0% (NIS-Teen, 2015-2017).

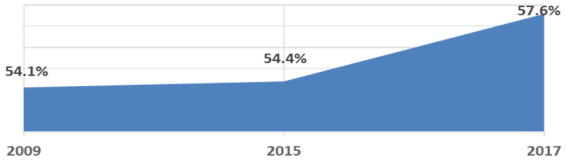


**Total surveyed: 851, results are weighted to be representative of all 13 to 17 year old's in PA*

Physical Inactivity

The percentage of adolescents aged 12-17 **not** physically active at least 60 minutes per day on five or more days, increased from 2009 to 2017. Compared to the national average, PA youth are less physically active. Female adolescents in PA report less frequent physical activity than male adolescents.

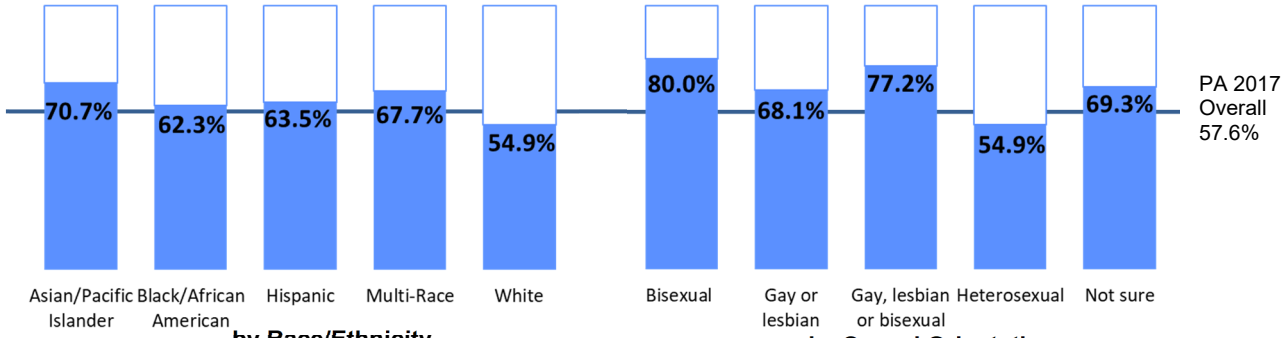
Youth Risk Behavior Survey • 2009-2017
% of adolescents aged 12-17 with **less than** 60 minutes of physical activity per day on five or more days



by Year
**Total surveyed: 8,740*

Additionally, a larger percentage of racial and ethnic minority youth as well as sexual minority youth report physical inactivity as compared to their White and/or heterosexual classmates (YRBS 2017).

Youth Risk Behavior Survey • 2017
Percent of adolescents aged 12-17 with <60 minutes of physical activity per day on five or more days

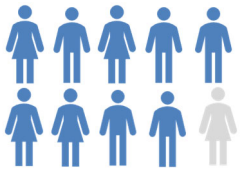


by Race/Ethnicity
**Total surveyed: 3,761*

by Sexual Orientation
**Total surveyed: 3,761*

Condom/Contraception Use

The percentage of adolescents aged 12-17 who reported not using both a condom and other form of contraception (IUD or hormonal) at last intercourse decreased slightly from 91.9% in 2015 to 86.8% in 2017. 90.0% of male adolescents reported not using both a condom and other form of contraception at last intercourse as compared to 83.7% of female adolescents in 2017 (YRBS 2015-2017).

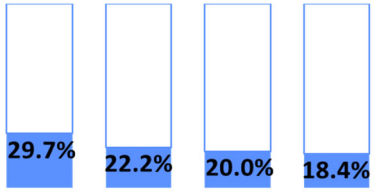


Nine of every 10 adolescents aged 12-17 in PA reported not using both a condom and other forms of contraception during their last sexual intercourse

Interpersonal Violence – Physical Fighting

PA is currently meeting the 2020 goal of reducing reports of physical fighting among adolescents aged 12-17 in the last 12 months to only 28.4% (PA is currently at 22.8% of youth reporting physical fights as of 2017) and has been consistently below the national average from 2009 to 2017. However, 28.9% of males reported engaging in physical fighting as compared to only 16.4% of female. Physical fighting was also more common among adolescents in ninth grade as compared to adolescents in older classes (YRBS 2009-2017).

Youth Risk Behavior Survey • 2017
Percent of adolescents reporting a physical fight within the last 12 months



by Grade
**Total surveyed: 3,761*

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Interpersonal violence – Sexual Violence

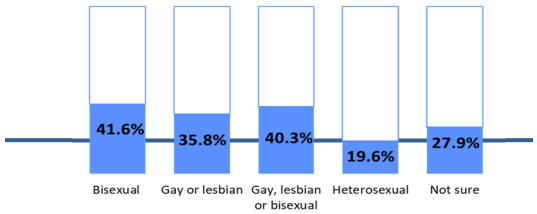
In 2017, 10.1% of PA youth aged 12-17 reported experiencing sexual violence compared to 9.7% nationally. When stratified by sexual orientation, experiencing sexual violence was 6.0% to 13.0%, more common among sexual-minority youth as compared to their heterosexual classmates (8.7%) (YRBS 2017).

Youth identifying as gay, lesbian or bisexual were 2.5 times as likely to report experiencing sexual violence than heterosexual youth

Bullying

Student reports of bullying on high school property in PA have increased by nearly 3.0% from 2009 to 2017 (19.2% to 21.7%) and the percentage of students who reported bullying was nearly twice as high among sexual-minority youth in 2017. PA has not yet met the 2020 goal of reducing bullying to 17.9%.

Youth Risk Behavior Survey • 2017
% of adolescents experiencing bullying on school property



PA 2017 Overall 21.7%

by Sexual Orientation
Total surveyed: 3,761

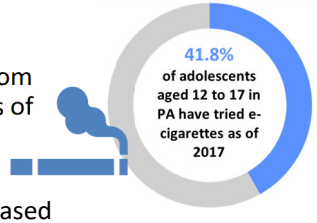
Electronic bullying among adolescents also increased from 14.4% in 2015 to 17.3% in 2017 (YRBS 2009-2017).

Obesity

As of 2016-2017, 16.8% of adolescents aged 10-17 in PA were reported as obese (BMI at or above the 95th percentile), a percentage that is slightly higher than the national average of 15.8% (NSCH 2016-2017).

Smoking, E-cigarettes & Vaping

The percentage of adolescents aged 12-17 in PA who smoke has dropped from 18.4% in 2009 to 8.7% in 2017. Yet, 11.3% of adolescents use e-cigarettes as of 2017 and more have tried them (YRBS 2009-2017).



Total surveyed: 3,761

Alcohol Consumption

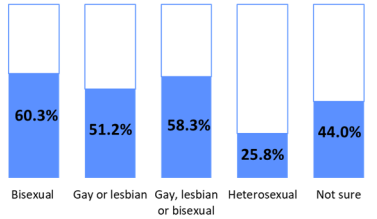
The percent of adolescents aged 12-17 who report consuming alcohol decreased from 2009 (38.4%) to 2017 (31.1%), similar to the national average. As of 2017, alcohol consumption increases with age (20.7% in 9th grade, vs. 41.4% in 12th grade), is more common among females (33.7%) as compared to males (28.6%) and among gay, lesbian or bisexual adolescents (39.6%) as compared to heterosexual adolescents (30.0%) (YRBS 2009-2017).

Depression, Suicidal Ideation and Suicide

The percent of adolescents who report feeling sad or hopeless increased in PA from 23.5% in 2009 to 29.4% in 2017. Females more commonly reported this (38.6%) than male youth (20.4%). Sexual-minority youth were more than twice as likely to report feeling sad or hopeless (51-60% of gay, lesbian or bisexual students) when compared to their heterosexual classmates (26.0%) (YRBS 2009-2017).

The percentage of adolescents reporting suicidal ideation in PA increased from 13.5% in 2009 to 15.0% in 2015 and 2017 and was more commonly reported among gay, lesbian or bisexual youth (38.5%) when compared to heterosexual youth (12.1%) (YRBS 2009-2017). This data is consistent with suicide rates, which have also increased from 2008 to 2016 in PA.

Youth Risk Behavior Survey • 2017
Percent of adolescents aged 12-17 reporting feeling sad or hopeless within the past 12 months

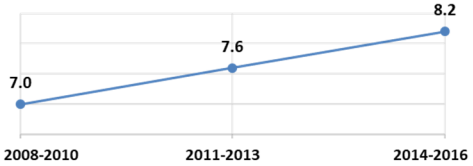


by Sexual Orientation
Total surveyed: 3,761

Adolescent Mortality

For the 10-14 age group, PA's mortality rate in 2017 was 14.2 deaths per 100,000 adolescents. For the 15-19 age group, the mortality rate in 2017 was 47.3 deaths per 100,000 adolescents. Although PA has met the 2020 goal for both rates, Black/African American adolescents aged 15-19 are almost two times as likely to die as compared to adolescents of another race ethnicity (PA Death Certificate Dataset 2012-2016).

PA National Vital Statistics System • 2008-2016
Rate of adolescent suicide (ages 12-19) per 100,000



by Year
Two year estimates, number of suicides per 100,000 adolescents

The leading causes of death among adolescents aged 15-19 in PA as of 2017 are:

1) **Assault and firearm discharge**
2) **Accidental poisoning by unspecified drugs or medications**
3) **Suicide or intentional self-harm**
4) **Injury from motor-vehicle accident/traffic**

Black/African American adolescents aged 15-19 are ~2 times more likely to die than White adolescents in PA

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HEALTH OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Children and Youth with Special Health Care Needs

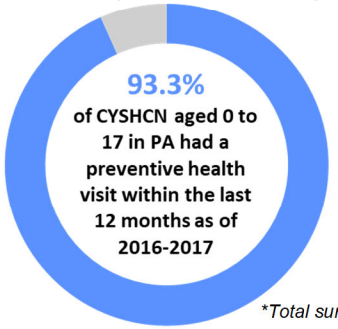
Children and youth with special health care needs (CYSHCN) are children ages 1 to 21 who have or are at increased risk for a chronic condition and who also require health care and related services of a type or amount beyond what is required by children generally. As of 2017, ~19.0% of children aged 0-17 in PA are CYSHCN (NSCH 2017).

Approximately 1 of every 5 families in PA has a child with special health care needs

- *IMPROVEMENTS & PROGRESS* –

Child Well Visit

As of 2016-17, 93.3% of CYSHCN aged 0-17 in PA had a child well visit within the last year compared to only 84.7% of children without special health care needs who had a well visit. This exceeds the PA overall percentage of 86.3% of children in PA who had a well visit within the last year and the national average of 82.0% (NSCH 2016-2017).



*Total surveyed: 3,761

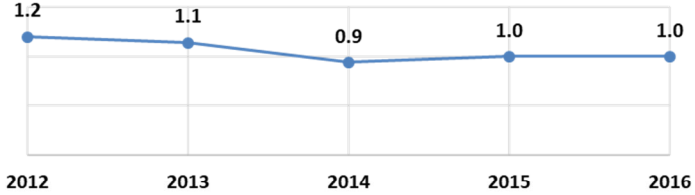
Behavioral Treatment and Counseling

As of 2016-2017, 4.5% of children aged 3-17 years with ADD or ADHD reported receiving needed behavioral treatment within the last 12 months, a percentage that is slightly higher than the national average of 3.9% (NSCH 2016-2017).

Infant Death Rate Attributed to Birth Defects

The 2020 goal is to reduce the rate of infant death attributed to birth defects to 1.30 deaths per 1,000 live births. In PA, the rate of death due to birth defects decreased from 1.20 deaths per 1,000 live births in 2012 to 1.00 deaths per 1,000 live births in 2016 – achieving the 2020 goal (CDC Wonder 2012-2016).

Centers for Disease Control – Wide-Ranging Online Data for Epidemiologic Research • 2009-2016
Rate of infant death attributed to birth defects per 1,000 live births



by Year

Number of infants deaths attributed to birth defects per 1,000 live births

-*ONGOING HEALTH ISSUES & DISPARITIES*-

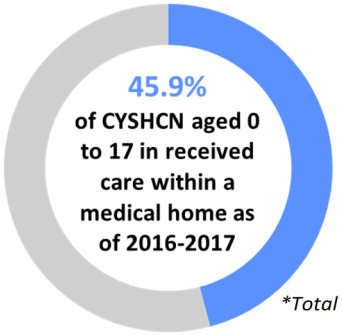
Access to Coordinated Health Care

As of 2016-2017, 16.5% of CYSHCN aged 0-17 received health care in a well-functioning system in PA. Although this is higher than the national average of 15.7%, children without special health care needs in PA are still more likely to be receiving care in a well-functioning system (23.3%) than CYSHCN. Additionally, PA has not yet met the 2020 goals of increasing the percentage of CSHCN who receive care in a well-functioning system to 22.4% among children aged 0-11 and to 15.1% among children aged 12-17 (NSCH 2016-2017).

In 2016-2017, 16.5% of children and youth with special health care needs aged 0-17 in PA reported receiving health care in a well-functioning system

Medical Home

As of 2016-2017, 45.9% of CYSHCN aged 0-17 report receiving care within a medical home in PA compared to 49.2% of children without special health care needs. Although this percentage is above the national average for CYSHCN (43.2%), it is below the 2020 goal of 51.8% (NSCH 2016-2017).



*Total surveyed: 1,522

Transition to Adult Health Care

As of 2016-2017, 15.8% of CYSHCN aged 12-17 reported receiving the services necessary to make the transition to adult healthcare in PA compared to 16.3% of youth without special health care needs. The percentage for CYSHCN is below the national average of 16.7% (NSCH 2016-2017).

Inadequate Access to Needed Health Care

As of 2016-2017 6.5% of CYSHCN aged 0-17 reported not receiving needed healthcare in PA. Although this percentage is lower than the national average (8.1%), it is higher than the percentage reported by children without special health care needs; in 2016-2017 only 1.0% of children without special needs in PA reported not receiving needed healthcare (NSCH 2016-2017).

6.5% of children and youth with special health care needs aged 0 to 17 reported not receiving needed healthcare in 2016-2017

Physical Activity

As of 2016-2017, 17.6% of CYSHCN aged 6-17 reported participating in 60 minutes of physical activity daily compared to 26.7% among children without special health care needs. The percentage for CYSHCN is below the state and national averages (NSCH 2016-2017).

Adverse Childhood Experiences (ACES)

Adverse childhood experiences (ACES) are events that cause stress or trauma in a child's life. The National Survey of Children's Health asks parents whether their child has experienced one of the following ACES:

1) Parent or guardian divorce or separation;
2) Death of parent or guardian;
3) Jail time for parent or guardian;
4) Witnessed/heard violence between parents;
5) Victim or witness of neighborhood violence;
6) Lived with someone with mental illness;
7) Lived with someone with a drug/alcohol problem;
8) Unfair treatment because of race/ethnicity;
9) Hard to get by on family's income

Three of every 10 children and youth with special health care needs were reported by their parents as having experienced two or more adverse childhood experiences

In 2016-2017, 33.0% of CYSHCN in PA aged 0-17 were reported by their parents to have experienced two or more ACES as compared to only 15.9% of children without special health care needs experiencing two or more ACES (NSCH 2016-2017).

Adequate Health Insurance

The National Survey of Children's Health characterizes "adequate health insurance" as covering needed services and providers and reasonably covering costs. As of 2016-2017, 77.9% of children aged 0-17 were reported as having adequate health insurance in PA. Yet, CYSHCN were less likely to have "adequate" health insurance in Pennsylvania (68.6%) when compared to children without special health care needs (80.2%).

Bullying

As of 2016-2017, a higher percentage of CYSHCN aged 6-17 were bullied by their peers (34.1%) as compared to children without special health care needs (14.2%). (NSCH 2016-2017).

Tooth Decay

In PA, 17.5% of CYSHCN aged 0-17 reported having tooth decay or a cavity as compared to 10.6% of children without special health care needs. This exceeds that state overall percentage of 12.0% (NSCH 2016-2017).

Obesity

As of 2016-2017, 28.4% of CYSHCN between the ages of 10 and 17 in PA were obese (BMI at or above the 95th percentile) as compared to 13.1% of children without special health care needs who were obese (NSCH 2016-2017).

SURVEY AND FOCUS GROUP DISCUSSIONS: **LISTENING TO FAMILY VOICES**

Web Survey

From May 30, 2019 to June 28, 2019, the BFH requested input from providers, service recipients and their families on experiences with the health system in PA and the social and environmental factors influencing their health. The survey was distributed through provider e-mail distribution lists and through the Department of Health's Facebook and Twitter pages. It was available in both English and Spanish.

We heard from 554 Pennsylvanians

172 service recipients
and
382 health providers

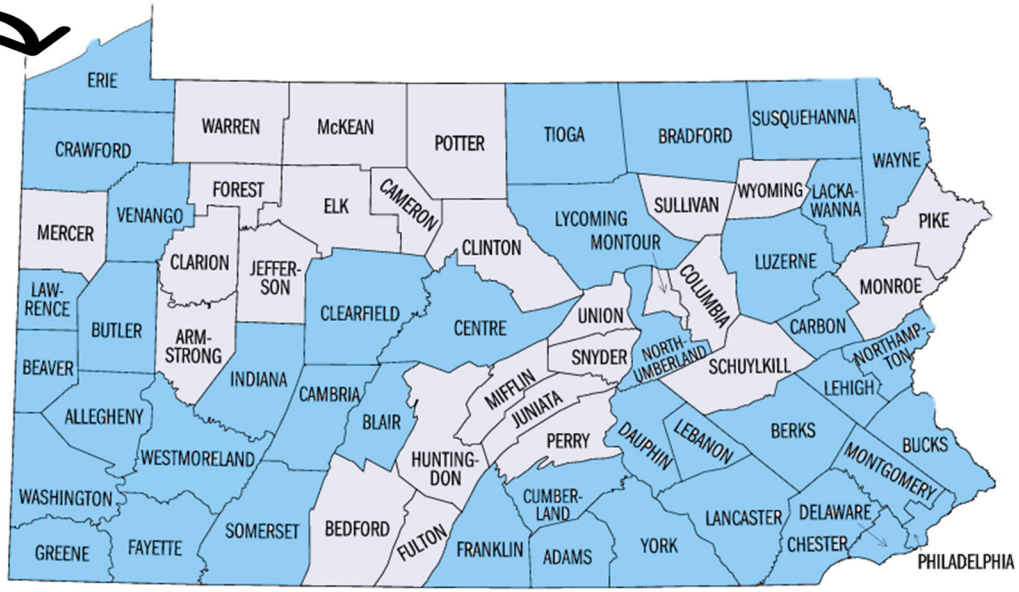
Service Recipients

90.2% of respondents identified as female and **61.2%** as mothers

9.8% of respondents identified as male and **21.4%** as a parent, guardian or caregiver

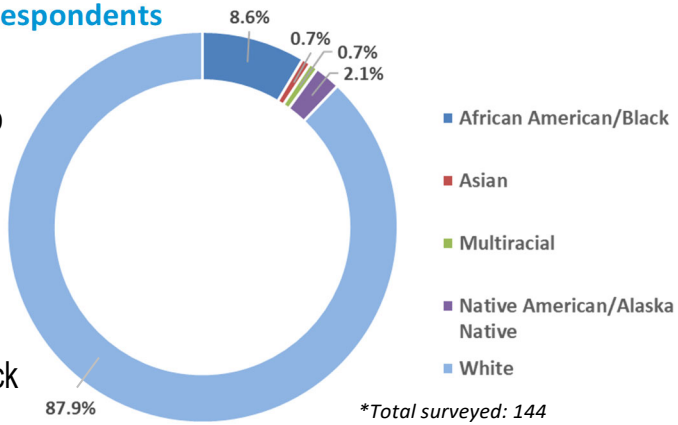
Service recipients who responded to the survey resided in 41 of PA's 67 counties

Providers reported serving maternal and child health populations statewide



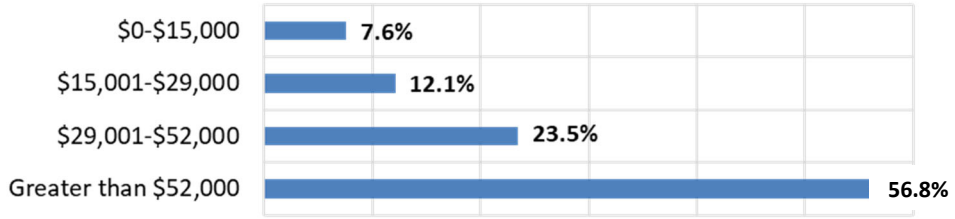
Demographics of Service Recipient Respondents

Most service recipients who responded to the survey identified as White or African American/Black



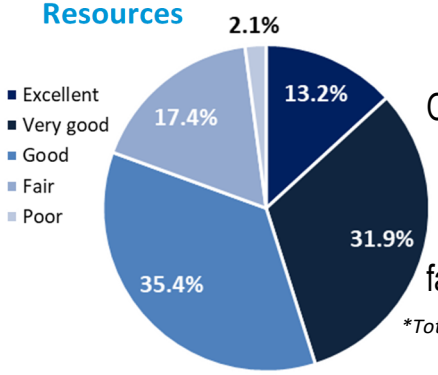
*Total surveyed: 144

Household Annual Income of Service Recipient Respondents



*Total surveyed: 132

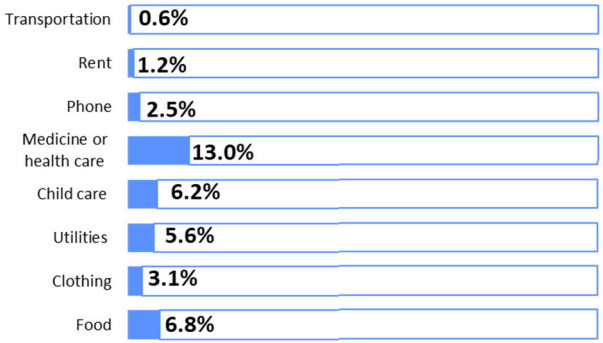
Health, Healthcare and Needed Resources



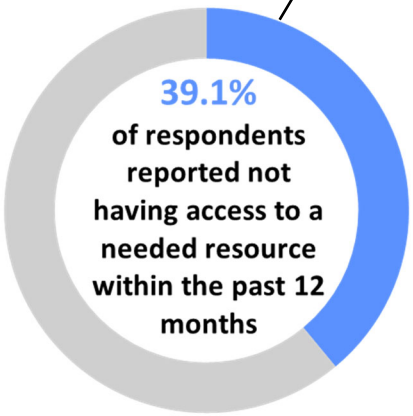
Overall, **45.1%** of respondents felt that their overall health was Excellent or Very Good; **54.9%** felt their health was good, fair or poor.

Total surveyed: 144

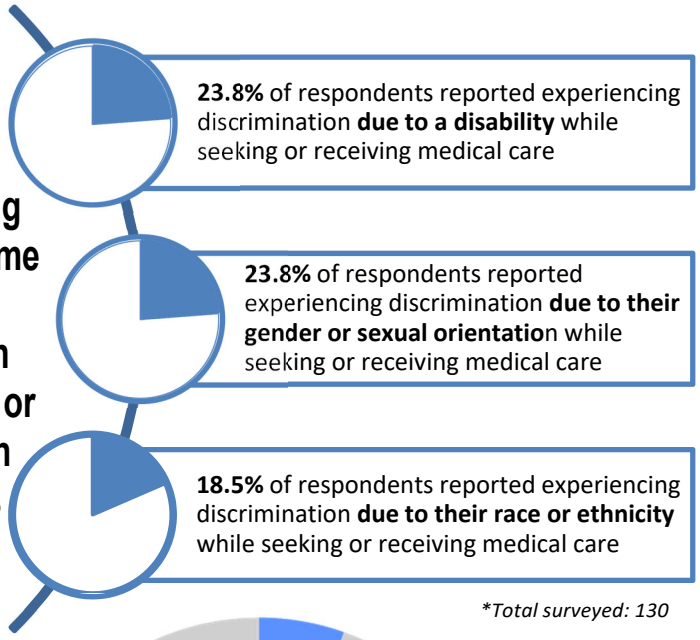
When it was really needed, we did not have the following during the past year:



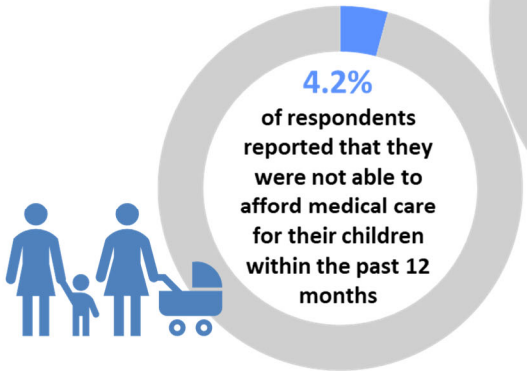
Total surveyed: 161

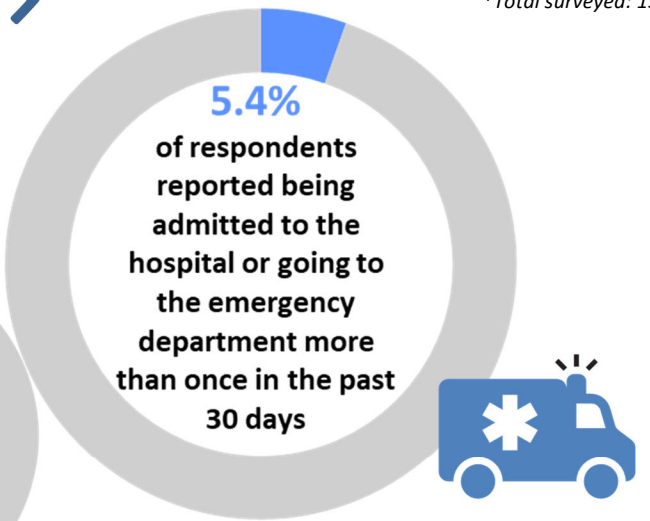


25% of all respondents reported having experienced some form of discrimination while receiving or seeking health care services



Total surveyed: 130





Total surveyed: 130

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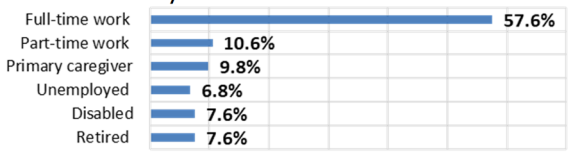
Economic Stability & Environment

- Employment

Although most respondents reported working full-time, many respondents also reported either part-time work or no work due to caregiving responsibilities, unemployment or disability.

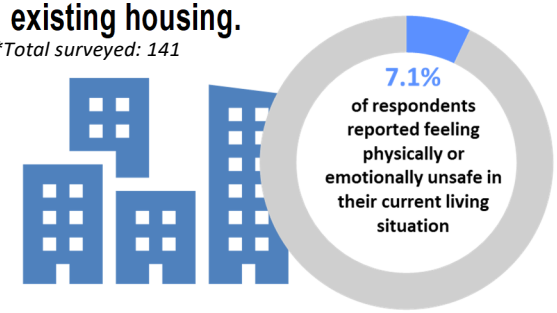


Total surveyed: 132

- Housing stability and security

11.3% of respondents reported not having housing or being concerned about losing their existing housing.

Total surveyed: 141



Total surveyed: 126

- Health insurance

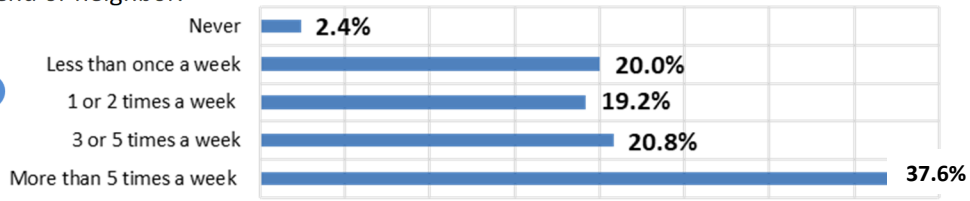
Although 92% of respondents reported having health insurance, 22.8% reported struggling to afford deductibles or co-payments during the past year.

Total surveyed: 130

Social and Community Context

- Social isolation

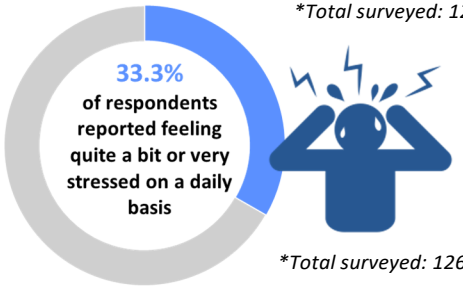
Social isolation and lack of contact or support from a community can have effects on health. 22.4% of persons surveyed reported never or very infrequently (less than once a week) seeing or talking with a friend or neighbor.



Total surveyed: 125

- Stress

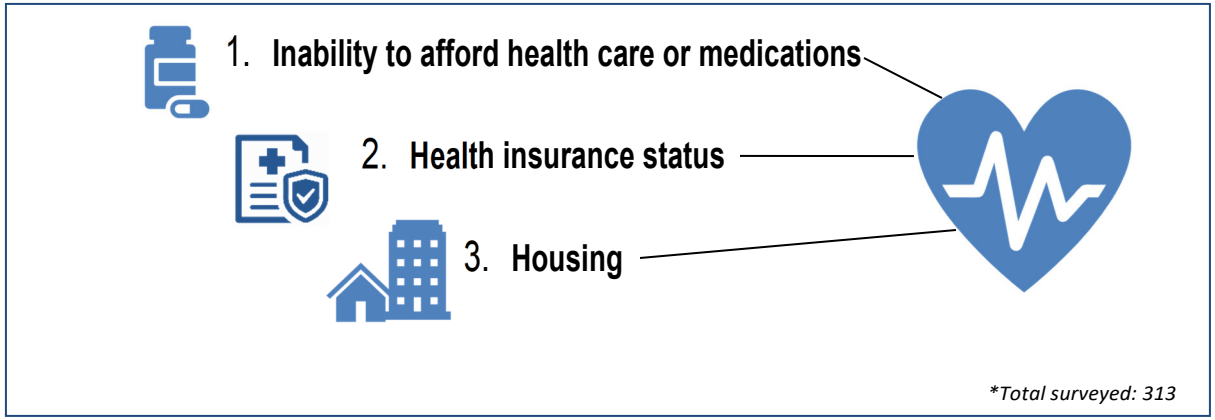
Stress is often associated with nervousness, anxiety or inability to sleep. Constant stress can impact health. Only 4% of respondents reported never feeling stressed. One third of all respondents reported feeling quite a bit or very stressed on a typical day.



Total surveyed: 126

• Providers

Providers indicated that the top three factors that they perceived to have the most significant negative impact on the health of patients in their network of care were:



Total surveyed: 313

pennsylvania
DEPARTMENT OF HEALTH

Focus Groups

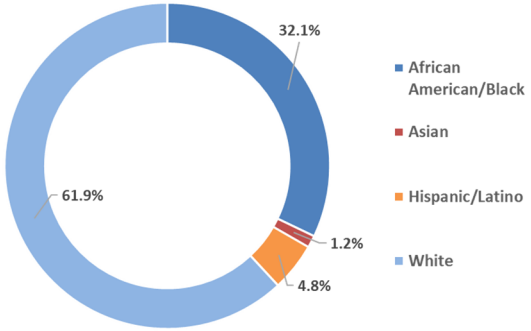
During the months of July and August 2019, seven focus groups were held across the state with service recipients and providers to gather more in-depth information on what was learned from the web survey – in particular, the factors that influence health and health outcomes among maternal and child health populations in Pennsylvania.

Demographics of Participants

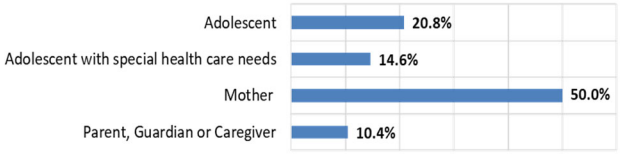
We engaged 88 service recipients and providers in focus group discussions.

84.1% of participants identified as female, **11.4%** as male and **4.5%** as genderfluid or transgender

Most participants identified as White or African/American Black.



When asked to describe themselves, service recipient participants identified as being a(n):



Women, mothers and their providers described the following common themes:

- **Health services should be accessible**
  - "It is important that services are easy to get to"
  - "Have to re-schedule even if you are a little bit late due to transit"
  - "Providing transportation to medical care or visits within the neighborhood or community are important"
- **Support and services during and after pregnancy are important**
  - "We need ongoing access to care, not just when pregnant"
  - "Access to birth support, postpartum and breast-feeding/lactation support is needed"
- **Experiences with economic instability negatively impact health**
  - "Affects my health when I have no cash for bus or Uber/Lyft to get to the doctor"
  - "Taking off of work to go to the doctor is not possible – I cannot afford it"
  - "You cannot separate poverty from quality health"
  - "Working two jobs and I still cannot make ends meet"
  - "I had no maternity leave, had to go right back to work"
- **Experiences with discrimination are common and it occurs while seeking health care**
  - "We were met with surprise that we were educated about our health – didn't expect it because we were a Black family"
  - "Women who are pregnant and of child-bearing age often don't receive good care"
- **Do not feel heard or taken seriously in health-related decision-making**
  - "I have been to the hospital and my concerns have been brushed off"
  - "I didn't feel like I had any other options for the birth"
  - "Had to do what the doctors want, not what was best for my family"
- **Lack of or inadequate health insurance impacts access to health care**
  - "When I didn't have health insurance I didn't go to the hospital"
  - "My insurance is just as bad as being uninsured – huge bills that should have been paid were not covered"
- **Access to mental and behavioral health services is important**
  - "Programs addressing trauma and mental health are needed"
  - "Mental health services are important"

Adolescents, youth and their providers described the following common themes:

- **Youth do not feel heard or taken seriously in health-related decision-making**

"The doctors don't take me or my medical concerns seriously"
"My doctor would only listen to my mom, not to me"
"Youth feel decisions are made about them with no one listening to their thoughts or feelings"

"Transportation is a huge barrier for youth"
"My appointments were too far away and hard to get to"
"Bus routes are not available or widespread in many counties and, even if they were, youth lack funds for a bus pass"
"The specialist was too far away so my health issue was never taken care of"

- **Needed health services are inaccessible due to transportation barriers**

- **Mental and behavioral health services are important**

"I cannot feel better if I am not healthy mentally"

"Bullying is horrible stuff and it makes you depressed – people say to brush it off, but it affects how you feel"

"Youth who have symptoms of anxiety, but no diagnosis may self-medicate with drugs and alcohol"
"There is a lack of mental health providers for youth and there are no free services"

"Most youth either are not aware of their health insurance status or won't use it for fear of their parents finding out"
"I had to wait for insurance to kick-in, so I couldn't go to the doctor"
"Every time that I got sick, I stayed home and skipped school because the hospital is too expensive"

- **Lack of access to health insurance and fear of medical expenses limit use of the health care system**

- **Lack of access to basic resources and housing negatively affects health**

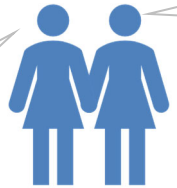
"Youth often don't have a choice in the environment in which they are living – it's hard to make change"
"Lack of housing, food and clothes is not uncommon and homeless youth under 18 often cannot find or afford housing"

"We struggled to afford electric and water and didn't have a working stove – it was a struggle"

"I live with my grandparents because my parents cannot afford housing"

- **Culturally competent and sensitive care is important**

"Important to make it evident that you are an LGBTQ provider when someone walks through the door"
"More education and training are needed to help providers understand that youth have different and diverse backgrounds"
"The treatment didn't go well because they did not ask the right questions"



Children and Youth with Special Health Care Needs (CYSHCN), their families and their providers described the following common themes:

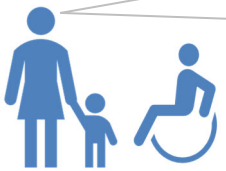
- **High rates of doctor and support staff turnover and lack of continuity of care negatively affects health**

"Once a child begins to open up in therapy – turnover occurs"
"Even though it is thought of as a 'service' it is about the relationship that must be built in order for it to be effective – changeover of staff causes more issues, including breakdowns"
"The high turnover of home health support staff is problematic"

- **Experiences with discrimination are common and it occurs while seeking or receiving health care**

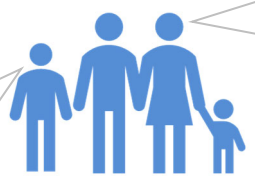
" When the health professionals lack knowledge of the conditions – it can lead to discrimination"
"Adults tend to talk slower just because they use a wheelchair – they assume cognitive delays"
"My child was not allowed to attend social events because of their condition"
"The doctor downplayed the complaints and deemed them unimportant because of their condition"

- **There is a lack of adequate transportation to needed health services**



" Transportation is not easy and is a huge issue – especially in rural areas"
"Services at daycare center or at home would make it so that we don't have to travel to appointments or find transportation"
"Families go into debt purchasing a vehicle that meets the needs of their child"
"After waiting for months to get an appointment, the transport did not come"

- **High cost of insurance and inadequate insurance impact which needed services CYSHCN are able to receive**



"When we do have health insurance, copayments can be so high that we avoid going to the doctors"
"Some doctors don't want to take Medical Assistance"
"The cost of needed specialized therapies and behavioral health services are often not covered"
"Fighting with insurance companies is an added expense to the family"

- **Transition from pediatric to adult care is important**

"Coordination between adult care and pediatric practitioners has been extremely valuable for transition of care"
"There is a gap in provider training for preparing pre-adolescents for adulthood"
"Transition is difficult because some services are lost as an adult"

- **Caregivers experience high levels of stress and lack of respite impacts their relationships and health**

"Parenting is already stressful, and special needs parenting is full of anxiety"
"Two parent households divide appointment responsibilities and go in different directions – straining their relationship"
"So worried about meeting the child's needs that parents needs cannot matter"
"Advocacy and parent support groups are important – parents caring for adult children need respite"

- **Access to dental services is limited due to lack of dentists/orthodontists willing to see CYSHCN**

"Dental care is important, specifically dental care professionals who are willing to see a child with special needs"
"We struggled to find a dentist who would serve the child and take their insurance"
"There is a lack of dental care for children with special health needs"