

Data Placemats Instructions

Every five years, the Bureau of Family Health (BFH) must conduct a state-level, comprehensive assessment of the health status of women, individuals who are pregnant or have recently given birth, infants, children, adolescents, and children and youth with special health care needs as a requirement of Pennsylvania's Title V Maternal and Child Health (MCH) Services Block Grant. This assessment identifies the priority health needs that will guide state and local public health work funded by Title V. During this assessment, the BFH also evaluates its capacity to serve the MCH populations. As part of our mission, the BFH is asking for input from the public on the most important MCH needs that should be addressed in Pennsylvania.

Purpose of the Data Placemats

Each data placemat defines and summarizes at least one of the issues or health needs being considered as a potential priority to be addressed based on results from the analysis of available health data as well as the feedback received from families, service recipients, and providers since 2020. 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. However, it is important to note, the topics described on the data placemats do not exist in isolation and may be related to many other health needs. **The BFH and stakeholders will use this data to inform the selection of the seven to 10 specific priority health needs that will be addressed by the Title V program over the next five years.**

There are a few ideas to keep in mind during your review of the data placemats:

Our Mission

The Department of Health's BFH has a mission to equally protect and equitably promote the health and well-being of pregnant people, their partners, their children, and all families in Pennsylvania.

Health Equity

The BFH and its Title V Program acknowledge that systemic racism, other forms of oppression, and social, environmental, and economic inequities contribute to poor health outcomes and have a greater impact on health than individual choices, behaviors, or even their access to healthcare. These factors and experiences of discrimination impact a person's health throughout their life and can result in trauma that impacts health across generations. Certain communities and groups that have experienced historic and ongoing discrimination and oppression often experience a higher burden of negative health outcomes as compared to others. Differences in health outcomes will be highlighted in these documents as these differences must be identified and addressed for all people to attain health and wellness. It is important to note that these differences in health outcomes by race, ethnicity, income, gender identity, sexual orientation, and other characteristics are the result of systemic, unfair, and unjust circumstances.

Social Determinants of Health

Social determinants of health (SDOH) are the nonmedical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies, racism, climate change, and political systems. The SDOH are referred to in the “Factors Influencing the Issue” section.

How to Read the Data Placemats

The “**Domain**” name refers to the MCH populations as established by the Health Resources and Services Administration (HRSA):

Infants - Infants are children in their first year of life – within 365 days of birth.

Children – Children are defined as anyone between the ages of 1 and 21.

Adolescents - Adolescence is the period of growth and development between childhood and adulthood. For the purpose of the data placemats, adolescents are defined as youth between the ages of 12 and 21.

Children and Youth with Special Health Care Needs (CYSHCN) - Children between infancy and age 21 who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

Women/Maternal - With one exception, this population domain appears as **Pregnant and Postpartum People** on the data placemats. HRSA defines a pregnant woman as a female from the time that she conceives to 60 days after birth, delivery, or expulsion of fetus. However, the data placemat discusses the health status of women, child-bearing people, pregnant people, and people who have recently given birth or become parents. The Title V program provides services and support to all people who can or do give birth including transgender and nonbinary birthing people. For some indicators, the term women may be used if that is how the survey or data system refers to the respondents. The Title V program also recognizes the right of every person to decide whether to have a child. While indicators in this domain are described in relation to pregnancy, Title V aims to advance the health and well-being of all families. The BFH acknowledges that the state of being pregnant, the process of giving birth or otherwise ending a pregnancy, and the act of parenting and caregiving are inclusive of all genders while also recognizing that data sources may not be.

The “**What is _____**” section lists and describes some important terms and concepts that appear throughout the document. Knowing these terms is important to understand the topic and being able to provide input. It is also important for everyone to have a common understanding of the terms so that they are on the same page when discussing the topic.

The “**Why addressing _____ is important**” section lists some reasons why the Department is looking for input on the topic and why addressing it could be a priority in the upcoming grant cycle.

The “**Factors Influencing the Issue**” section describes factors, such as specific Social Determinants of Health, that impact and are related to the topic. Please see above for a definition of Social Determinants of Health.

The “**Charts and Data Takeaways**” section displays measures of data specific to the topic, as well as trends in the data. Even if overall trends are improving, this may not be the case for all populations and inequities are identified throughout. The data takeaways summarize some key points to think about in the discussions around priorities. This is important data to consider, but participants are also encouraged to use any other information and experiences they may have. Measures may be broken down by select demographic characteristics, such as race/ethnicity, age, socioeconomic status, sex, gender identity, and sexual orientation. Primarily statewide data is used in the Charts/Data section because the Title V program must consider the whole state when it establishes the priorities that guide its state action plan. As Title V assesses whether its priorities remain relevant and responsive to statewide needs, it is necessary to assess health indicators for the state. When possible, disparities by geographic region or county are highlighted for certain measures. The BFH recognizes that health status is dynamic and that these briefs only provide a snapshot of indicators of health at a point in time. The BFH has tried to use the most recent data in these briefs and is committed to releasing updated versions as updated data are made available.

The **Data Placemats - References** encompasses all data sources and citations referenced on the placemats.

What happens next?

The seven to 10 priorities that are selected through the needs assessment process will inform which issues state and local Title V programs, staff, and grantees address over the next five years (2026-2030). Maternal and child health partners and Title V staff will develop and implement programs and strategies that aim to promote and improve the health and well-being of women, individuals who are pregnant or have recently given birth, children, adolescents, children and youth with special health care needs, and their families.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Behavioral Healthcare During Pregnancy and Postpartum

What is Behavioral Healthcare During Pregnancy and Postpartum:

Behavioral Health generally refers to mental health and substance use disorders, life stressors and crises, and stress-related physical symptoms. Behavioral healthcare refers to the prevention, diagnosis, and treatment of those conditions¹.

- **Mental Health** refers to a person's emotional, cognitive, and psychological wellbeing². **Perinatal depression**, depression that occurs during pregnancy, has been associated with preterm birth, low birth weight, and fetal growth restriction³. **Postpartum depression**, which may be mistaken for baby blues, usually develops within the first few weeks after giving birth⁴. Symptoms may result in issues with breastfeeding, difficulties in relationships, or increased substance use⁵.
- **Substance Use Disorder (SUD)** is the repeated misuse of alcohol or drugs⁶. The primary focus for this topic is medications or drugs such as opioids, benzodiazepines, and barbiturates through prescription, medication-assisted treatment, or illicit use.

Why addressing Behavioral Healthcare During Pregnancy and Postpartum is important:

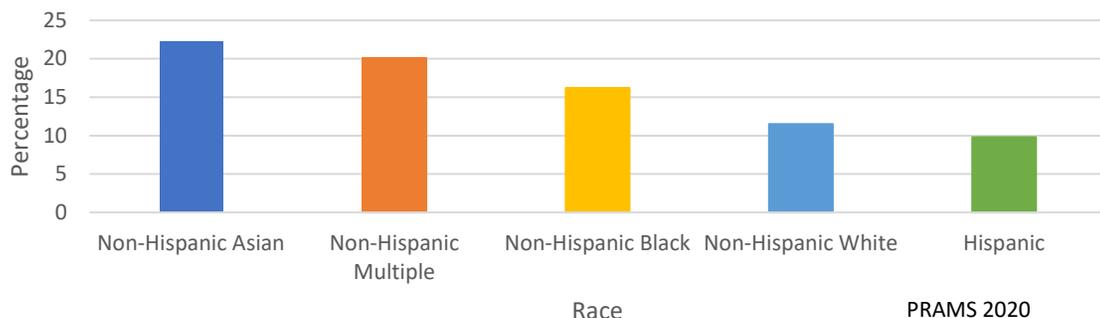
- Behavioral health conditions are associated with several adverse health behaviors and outcomes, including poorer maternal and infant bonding, decreased breastfeeding initiation, and delayed infant development^{5,8}.
- Behavioral health conditions are one of the leading underlying causes of pregnancy-related deaths nationally⁹.
- Postpartum depression rates are highest among people with less than a high school education, people covered by Medicaid, and Black birthing people¹⁰.
- Untreated behavioral health conditions during pregnancy have the potential to adversely impact both maternal and infant health^{3, 11}.
- Discrimination and racial bias may be present among providers which impacts care and treatment decisions for substance use disorder¹².

Factors Influencing the Issue:

- Risk factors for postpartum depression may include perinatal complications such as gestational diabetes and preterm birth, poor hospital treatment during birth¹³, issues related to the social determinants of health such as lack of social support and high life stress, experiences with trauma or abuse, prior history of depression¹⁴, unplanned pregnancy, and prior history of depression or mental health disorders^{13, 15}.
- The experience of racism or racial discrimination and the experience of emotional upset in the year prior to birth, may increase the risk of a diagnosis of perinatal¹⁶ or postpartum depression^{17, 18}.
- Stigma associated with behavioral health and SUD at the individual, intrapersonal, and institutional level during pregnancy and the postpartum period, may create barriers to obtaining treatment, cause social isolation, and increase harm for the pregnant person, the infant, and family^{12, 19, 20}. Additionally, provider bias and legal consequences may impact access to care and treatment^{7, 20}.

Charts and Data Takeaways:

Percent of Birthing People Who Experience Postpartum Depressive Symptoms Following a Live Birth by Race/Ethnicity



Differential prescribing has contributed to higher rates of opioid use disorder among white birthing people²¹.

Mental Illness and Substance Use Disorder Among Women in Pennsylvania

1) In 2018-2019, among those ages 18-49, 10.7% reported misusing prescription psychotherapeutics (pain relievers, tranquilizers, stimulants, or sedatives) or using illicit drugs in the past year²².
2) In 2020-2021, among those ages 18-44, approximately 21% binge drank or drank heavily in the past 30 days²³

9.5% of adult females reported the use of illicit drugs in the past 30 days²⁴

In 2020-2021, among those ages 18-44:

- 1) 11.6% with a recent live birth reported experiencing depressive symptoms²⁵.
- 2) 22% reported their mental health was not good 14 or more days in the past 30 days²⁶.

29.9% reported being told by a health professional that they have a depressive disorder²⁷.



The rate of depression during pregnancy **increased by 31% between 2016 and 2019**¹⁰.



Depression during pregnancy was most reported **among people with less than a high school education and among Black birthing people**¹⁰.



1 of 9 birthing people experience postpartum depressive symptoms and less than half of all people who indicated that they had depression during their most recent pregnancy asked for help from a healthcare worker¹⁰.



The annual rate of maternal opioid use disorder present at a hospital delivery per 1,000 delivery hospitalizations **increased from 15.47 in 2016 to 16.75 in 2019**²¹.

50%

Accidental poisoning (a category including drug overdose) was the cause for over 50% of pregnancy-associated deaths – considered a leading cause of maternal death for 2018 cases eligible for review by the Maternal Mortality Review Committee⁹.



Risk factors associated with maternal mortality in Pennsylvania **include behavioral health conditions, specifically substance use disorder**⁹.

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Bias, Racism, and Discrimination in Maternal Healthcare

What is Bias, Racism, and Discrimination in Maternal Healthcare:

- **Racism** is a system that structures opportunity and assigns value based on how a person looks or their ancestry. The results are conditions that unfairly advantage some and unfairly disadvantage others. Racism hurts the health of the nation by preventing some people the opportunity to attain their highest level of health. Racism may be intentional or unintentional. It operates at various levels in society: structural, institutional, interpersonal, and internalized¹.
- **Discrimination** is the unjust or prejudicial treatment of different categories of people, based on characteristics such as race, gender, age, or sexual orientation. A domain of racism, discrimination has been found to be associated with poor mental health, adverse physical health outcomes (e.g., hypertension, obesity, cardiovascular disease), and other poor health behaviors and outcomes^{2,3}.
- **Bias**: attitudes toward people of a specific group or association of that group with a stereotype⁴. Research suggests that widespread **implicit bias** (bias without conscious knowledge)⁵ among healthcare providers, including racial/ethnic biases as well as bias related to other patient characteristics such as age, gender, and weight, influence diagnosis and treatment decisions with impacts on health outcomes^{6,7}.

Why addressing Bias, Racism, and Discrimination in Maternal Healthcare is important:

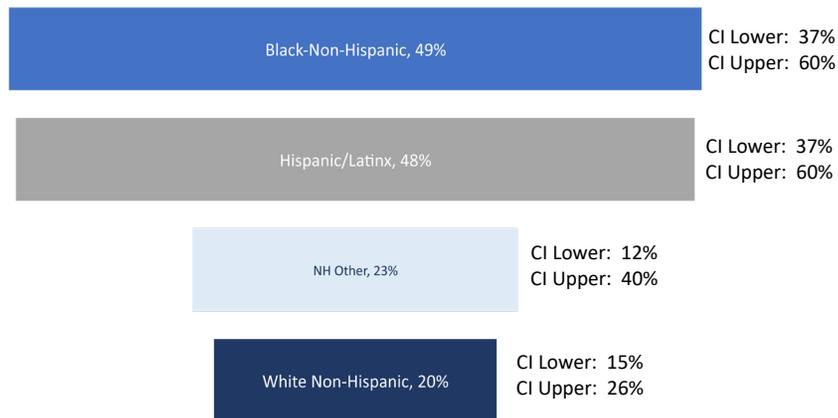
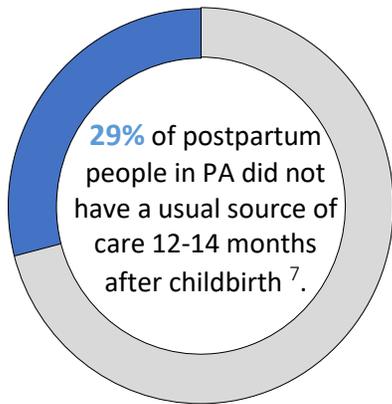
- Black birthing people were more likely to report experiencing mistreatment by healthcare providers during childbirth (defined as physical abuse, sexual abuse, verbal abuse, neglect and abandonment, poor rapport, loss of confidentiality, or lack of supportive care) than birthing people of other races⁸.
- Discrimination is a key risk factor for maternal mortality and morbidity, it is important to understand the experiences of racial discrimination, particularly in healthcare settings where pregnant and postpartum people seek care⁹.
- Provider bias may impact care and treatment decisions and can lead to mistrust in the healthcare system, particularly among people of color^{6,7,10}.

Factors Influencing the Issue:

- Historic and ongoing systems and social structures have created differences in access to resources, opportunities, and power in the U.S., which includes access to safe neighborhoods, economic and educational opportunities, and healthcare^{11,12}. Discrimination and racism are root causes of inequities across the political and social determinants of health, and both are barriers to health equity^{11,13}. Racism is more than just prejudice. It includes prejudice against people of color, as well as exclusion, discrimination against, suspicion of, and fear and hate of people of color¹.
- Social and economic inequities¹² in healthcare access, financial security, housing, the built environment and infrastructure, and social supports such as paid parental leave, resulting from systemic racism and discriminatory policies, may explain disparities in maternal health outcomes¹⁴.
- Reports of negative experiences with a healthcare provider are higher among birthing people compared to men¹¹. Birthing people of color who have been subject to racism or racial discrimination and have experienced emotional upset in the year prior to birth were more likely to report or be diagnosed with perinatal¹⁵ or postpartum depression^{16,17}. In addition, stressors from the COVID-19 pandemic, and living in an area of greater historical redlining has been analyzed to be associated with postpartum depression¹⁸.
- Providers of color are underrepresented in the healthcare workforce, due to systemic factors. Black, Hispanic, and Asian adults who have at least half of their visits with providers who share a racial and ethnic background reported having more frequent positive and respectful interactions¹².

Charts and Data Takeaways:

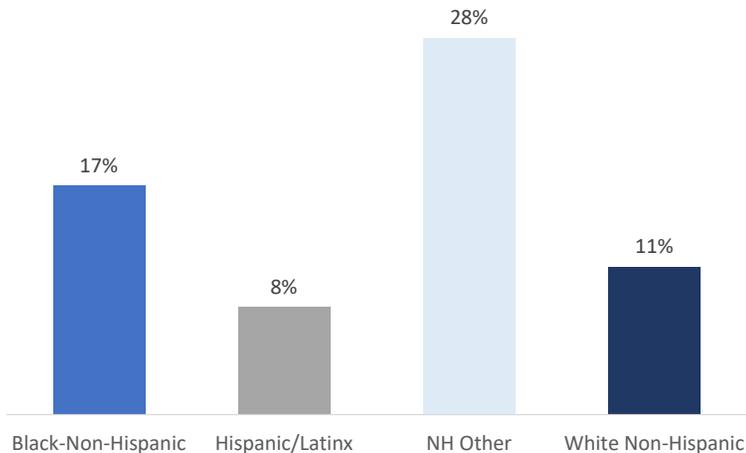
Percent of Postpartum People by Race with no Usual Source of Care After Childbirth



Source: Postpartum Assessment of Health Survey, 2020

"A usual source of care is a place or provider that an individual or family usually goes to when sick or in need of advice about their health. Emergency rooms and hospitals are not considered usual sources of care."

Percent by Race of any Reported Mistreatment by Care Providers in Childbirth



Non-Hispanic Black and Hispanic/Latinx respondents report higher levels of medical mistrust relative to Non-Hispanic White ⁸.

Source: Postpartum Assessment of Health Survey, 2020

Mistreatment based on the MCPC Scale and Mistrust is based on the GBMM



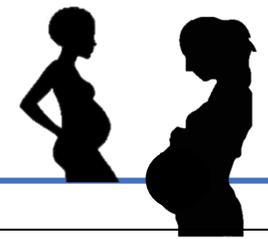
Approximately **13.0%** of people with a live birth indicated that they had experienced mistreatment by their care provider during childbirth in 2020 ⁸.



People identifying as Non-Hispanic Black were more likely to have experienced mistreatment by healthcare providers during childbirth, than people identifying as Non-Hispanic White ⁸.



In 2020, approximately **1.8%** of people with a recent live birth indicated that they were treated unfairly or had experienced discrimination when seeking healthcare after birth. Among this group of birthing people, **39.2%** indicated that they felt the main reason that they were treated unfairly, or experienced discrimination was their race/ethnicity or skin color ⁸.



Severe Maternal Morbidity and Mortality

What is Severe Maternal Morbidity and Maternal Mortality:

Severe maternal morbidity (SMM) includes unexpected outcomes of labor and childbirth that can result in significant consequences for the birthing person's health¹. Complications associated with SMM can include extensive bleeding, heart issues, kidney failure, or infection, all of which may contribute to an extended hospital stay or other long-term health problems^{1,2}.

Maternal mortality is the death of an individual during pregnancy, or up to one year following the end of the pregnancy, regardless of the outcome of the pregnancy. Maternal Deaths may be determined to be pregnancy-associated or pregnancy-related. Maternal Mortality may also be referred to as **pregnancy-associated deaths**¹⁴.

- **Pregnancy-related death** is the death of an individual during pregnancy or within one year of the end of a pregnancy - regardless of the outcome, duration, or site of the pregnancy due to a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy. Pregnancy-related deaths are measured using the **pregnancy-related (maternal) mortality ratio**, which is an estimate of the number of maternal deaths per 100,000 live births¹⁵.

Why addressing Severe Maternal Morbidity and Maternal Mortality is important:

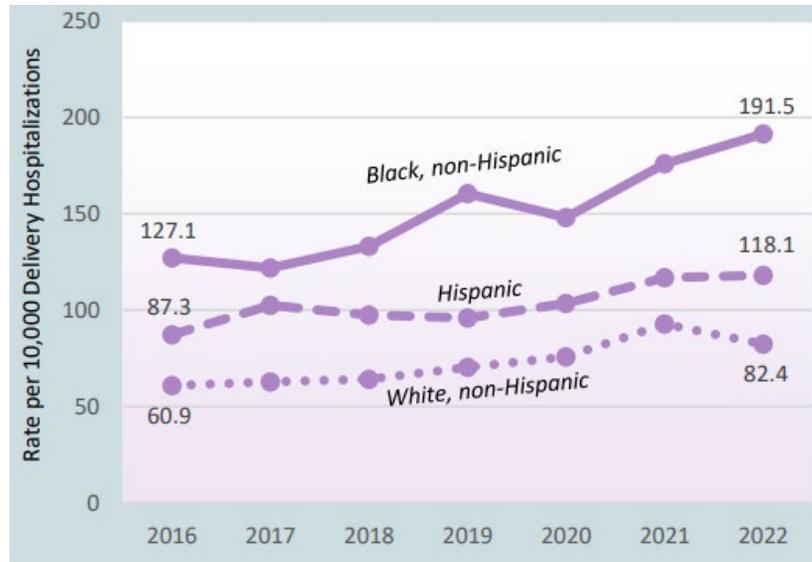
- SMM is significantly more common than mortality, may be life-threatening, and can impact maternal health for years afterward⁴.
- While maternal mortality is less common, it is a devastating event for families and communities⁵.
- Both SMM and maternal mortality are more common among Black birthing people and other people of color in Pennsylvania^{3,6}.
- Racial bias may be present among providers which impacts care and treatment decisions⁷.

Factors Influencing the Issue:

- Prenatal care may be delayed or not received due to lack of transportation to the clinic or doctor's office, not having enough money, or health insurance to pay for visits⁸.
- People identifying as Hispanic, people living in poverty, Medicaid recipients, and people with a functional limitation or disability may be more likely to experience transportation barriers when seeking healthcare⁹;
- In pregnancy, housing instability is associated with inadequate prenatal care and adverse birth outcomes, including low birthweight and preterm birth⁵. Access to safe, stable, and affordable housing is a social determinant of health and large disparities exist by race/ethnicity¹⁰ and socioeconomic status at both the state and national level, resulting from historical injustices like redlining^{11,12}.
- Disparities may be explained by social and environmental inequities in healthcare access/quality, housing, and social supports such as paid parental leave which result from racism and discriminatory policies^{11, 12, 13}.

Charts and Data Takeaways:

Rate of Severe Maternal Morbidity by Race and Ethnicity



11 of the 12 in-hospital deaths of the mother during a hospital delivery also had an SMM, 2021-2022⁶.

Source: Healthcare Utilization Project, Severe Maternal Morbidity 2022 – Pennsylvania Health Care Cost Containment Council, 2016-2022



The overall rate of SMM **increased by 40% between 2016 and 2022⁶.**

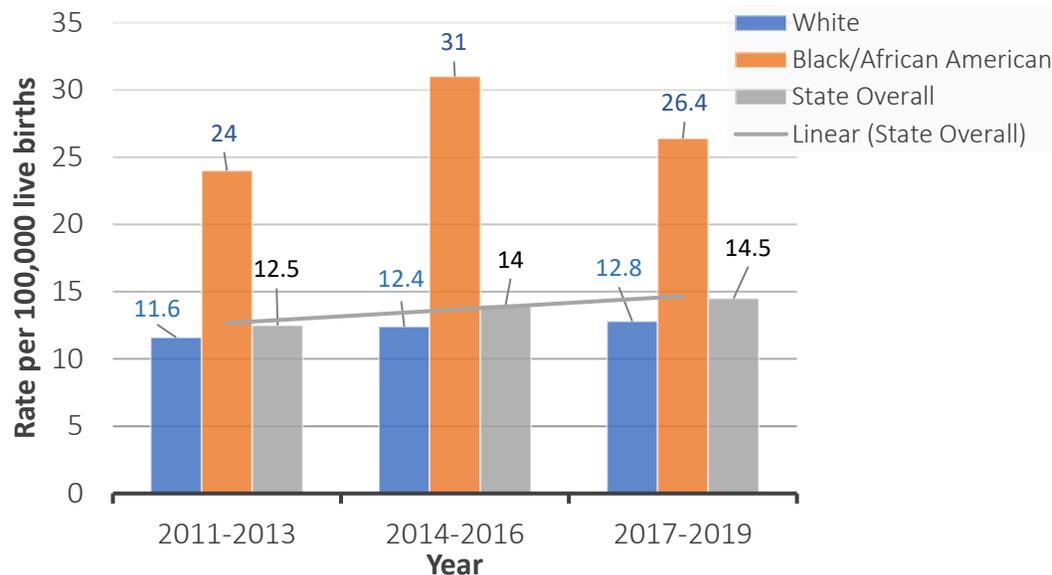


Pennsylvania's SMM rates are highest among **Black birthing people** as compared to people of other race/ethnicities and **is over twice as high as the rate of maternal morbidity among Non-Hispanic White birthing people⁶.**



Birthing people ages 40 and older in Pennsylvania, experience higher rates of SMM as compared to younger birthing people⁶.

Pregnancy-Related Mortality Ratio per 100,000 live births by year and maternal race/ethnicity



Source: Pregnancy Mortality Surveillance System, 2011-2019



Rolling five-year estimates between 2011 and 2019 suggest that maternal mortality rates have gradually **increased in Pennsylvania in recent years⁸.**



Black/African American birthing people are two times as likely to die during or up to one year following pregnancy as white birthing people^{3,8}.



Risk factors associated with maternal mortality in Pennsylvania **include behavioral health conditions, specifically substance use disorder³.**

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Infant Developmental Screening



What is Infant Developmental Screening:

Infant Developmental Screening is the process of looking at and monitoring infant development by using formal questionnaires or checklists based on research that asks questions about a child's development, including language, movement, thinking, behavior, and emotions^{1,2}.

Developmental screening can be done by a doctor or nurse, but also by other professionals in healthcare, early childhood education, community, or school settings¹.

Why addressing Infant Developmental Screening is important:

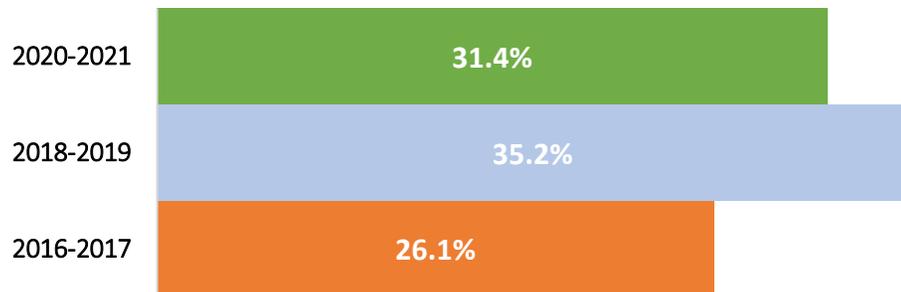
- A screening does not provide a diagnosis, rather, it indicates whether a child is on track developmentally and if a consultation with a specialist is needed¹.
- Developmental screenings identify children at risk of having or developing developmental delays, with the goal of improving outcomes through early intervention and referral to supportive services³. The results of a screening can help parents and community providers plan how to best support development of the child¹.
- Connecting parents and caregivers with developmental and behavioral specialists is an important next step if a child needs a formal evaluation and additional support from a specialist like a developmental pediatrician or a child psychologist⁴.
- Development of healthy social and emotional behaviors in infancy may prevent mental health problems and challenges during childhood and adolescence⁵.

Factors Influencing the Issue:

- Poverty, unstable housing, parental stress, and adverse events such as maltreatment, abuse, neglect, exposure to alcohol or substance abuse, violence, and/or trauma can have serious negative impacts on child development and behavior^{4,6}.
- Many factors may influence a child's likelihood of receiving a developmental screening including family structure, parents' income and/or educational attainment levels, living in a non-English speaking primary language household, and having a medical home⁷.
- Screening tools can help mitigate provider biases which may otherwise lead to dismissing developmental concerns⁸. The impact of a missed early diagnosis and lack of needed services can last a lifetime as disparities continue to compound, resulting in lifelong physical and mental health impairments⁹.

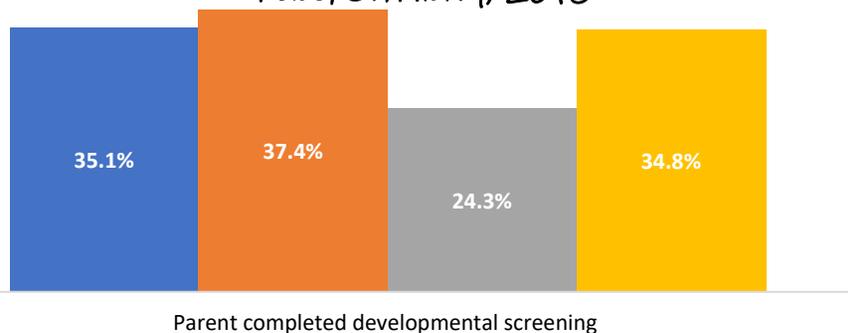
Charts and Data Takeaways:

Percent Of Pennsylvania Children Aged 9 through 35 Months Who Received A Developmental Screening Using A Parent-completed Screening Tool, 2022



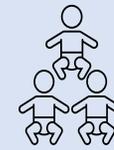
Source: National Survey of Children's Health

Percent Of Children Ages 9 through 35 Months Who Received A Developmental Screening Using A Parent-completed Screening Tool In The Past Year, By Race/Ethnicity, 2018



■ Hispanic ■ non-Hispanic White ■ non-Hispanic Black ■ non-Hispanic Other

Source: National Survey of Children's Health



Nearly 100% of all infants in the state receive **newborn screenings**, annually¹⁰.



Respondents to the Bureau of Family Health's annual survey noted **wanting increased parent/caregiver support and education on infant care, developmental milestones, and promoting infant health/well-being** from 2021 through 2023. This was the **top unmet need** identified in 2021, 2022, and 2023 for the infant health domain¹⁰.



Approximately **3 out of every 10 (30.4%)** children ages 9 through 35 months in Pennsylvania had received a developmental screening during 2016-2020¹¹.



Identification of development delays via **early screening is important for a child's health**. The percentage of children aged 9-35 months who received developmental screening via a parent-completed tool increased from **27.3% in 2017-2018 to 35.5% in 2019-2020**¹¹.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Infant Wellbeing and Protective Factors

What is Infant Wellbeing and Protective Factors:

Infant Wellbeing is a measure of the quality of the child's life, including how well the child is and how well the child's life is going. It may be assessed in different ways, such as health, economic status, family or social life, or safety and security concern. It may include both objective measurements such as poverty or morbidity rates as well as subjective ones such as curiosity, resilience, attachment to caregivers, and contentment with life¹.

- **Protective Factors** are conditions or attributes in individuals, families, or the larger society that, when present, mitigate, or eliminate risk factors in families and communities and increase the health and wellbeing of children and families. They are usually grouped into six categories: nurturing and attachment; knowledge of parenting and child development; parental resilience, social connections; concrete support for parents and caregivers; and social and emotional competence of children².
- **Risk Factors** are variables that increase the likelihood of unwanted outcomes. Examples include poverty, parental depression, toxic parental stress, family conflict or violence, emotional neglect, and alcohol and other drug use in pregnancy³.

Why addressing Infant Wellbeing and Protective Factors is important:

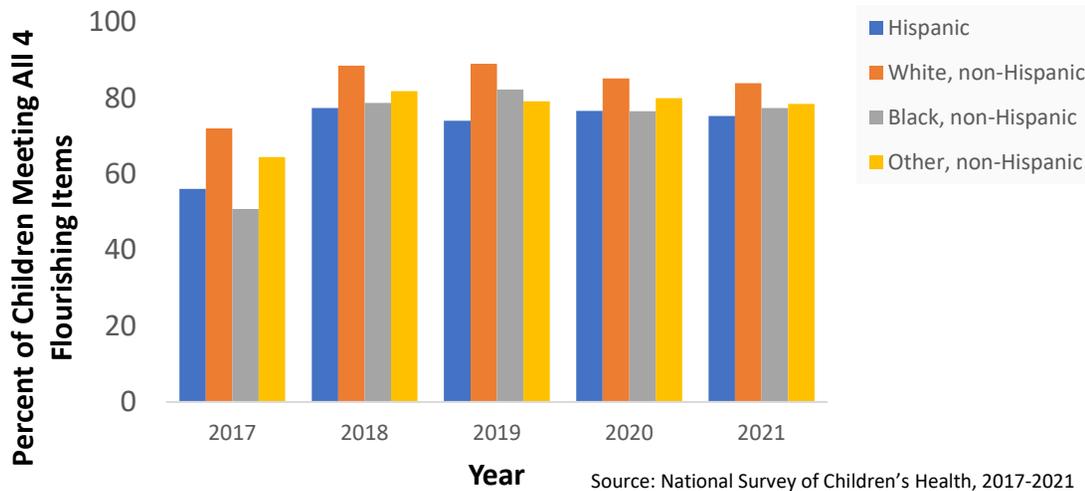
- A child's emotional growth and their ability to form social connections with other people begins during infancy⁴.
- Existing research suggests that infants with a strong parent-child relationship early in life are more likely to experience positive physical and mental health outcomes later in life⁴.
- Development of healthy social and emotional behaviors in infancy may prevent mental health problems and challenges during childhood and adolescence⁴.

Factors Influencing the Issue:

- Resilient families, or those that talk together about what to do when facing problems, work together to solve them, have strengths to draw on, and stay hopeful in difficult times, were more likely to report flourishing for their child⁵.
- Children living in families with higher levels of resilience and connection are much more likely to flourish. This is true for children across levels of household income, health status and exposure to adverse childhood experiences⁵.
- When social determinants of health are addressed, they can serve as protective factors⁶.

Charts and Data Takeaways:

Flourishing among Children ages 6 months through 5 years, 2017-2021



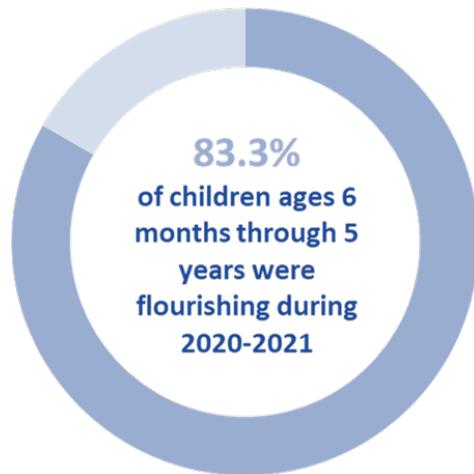
Data is limited but there is some suggestion that children with special health care needs (CSHCN) are less likely to be flourishing than non-CSHCN⁷.



Data is limited but there is some suggestion that Hispanic children were less likely to be flourishing than White or Asian children⁷.



Approximately 8 of every 10 children in Pennsylvania between the ages of 6 months and 5 years were flourishing during 2020-2021⁷.



Note: Flourishing captures a child's ability to cope with stressors and form healthy relationships. In children under the age of 5, characteristics of flourishing include curiosity, resilience, attachment to caregivers, and contentment with life.

Flourishing could not be looked at just for infants due to limited data.



Respondents to the Bureau of Family Health's annual surveys in 2021, 2022, and 2023 highlighted **increased parent/caregiver support and education on infant care, developmental milestones, and promoting infant health/well-being** as top unmet health needs for the infant health domain⁸.

Preterm Birth and Preterm-Related Mortality



What is Preterm Birth and Preterm-Related Mortality:

Preterm Birth is the birth of an infant before 37 completed weeks of gestation. Infants born preterm are at greater risk of immediate life-threatening health problems, as well as long-term complications and developmental delays. Preterm birth is a leading cause of infant death and childhood disability [both nationally and in Pennsylvania]¹.

- Some specific risk factors for preterm birth include delivering a premature baby in the past, being pregnant with multiples, tobacco use and substance use, and short time (less than 18 months) between pregnancies. Additionally, pregnancy complications can result in preterm birth because the baby has to be delivered early².

Preterm-Related Mortality is the death of an infant that is a direct consequence of the infant being born before 37 weeks of gestation¹.

Why addressing Preterm Birth and Preterm-Related Mortality is important:

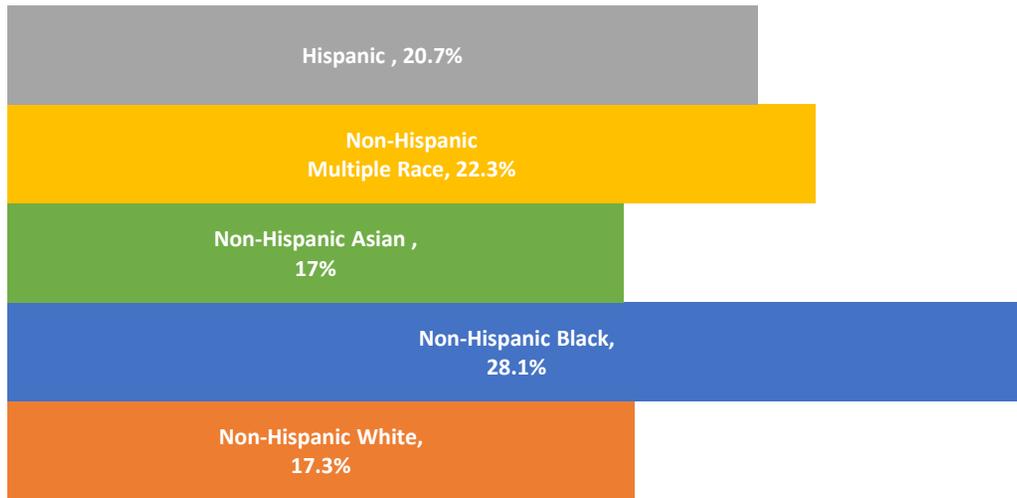
- A developing baby goes through important growth throughout pregnancy— including in the final months and weeks. For example, the brain, lungs, and liver need the final weeks of pregnancy to fully develop³.
- Premature birth can lead to long-term challenges for some babies, including intellectual and developmental disabilities⁴.
- Preterm birth is a leading cause of infant mortality. Preterm-related mortality can be prevented by reducing preterm birth as well as improving access to risk-appropriate perinatal care for infants born prematurely. Similar to preterm birth and overall infant mortality, there are significant racial/ethnic disparities in preterm-related mortality¹.

Factors Influencing the Issue

- Housing instability is associated with inadequate prenatal care and adverse birth outcomes, including low birthweight and preterm birth⁵. Additionally, this disparity may be explained by inequities in healthcare access, housing⁵, and social supports such as paid parental leave which result from racism and discriminatory policies as well as racial bias among providers which may impact care and treatment decisions^{6, 7}.
- Non-Hispanic Black birthing people are at least 1.5 times more likely to deliver a preterm birth baby than birthing people of other race and ethnic groups⁸.
- Preterm-related mortality rates are highest for infants born to non-Hispanic Black [birthing people] and account for most of the overall infant mortality gap as compared with non-Hispanic whites¹. The disproportionately high rates may be attributed to structural racism such as historic redlining⁹, chronic stress¹⁰, and persistent inequities in privilege and economic opportunity at both the individual and neighborhood levels^{11, 12}. Circumstances, experiences, and events occurring throughout a birthing person's life have an impact on their health, their birth outcomes, and the health of their children¹³.

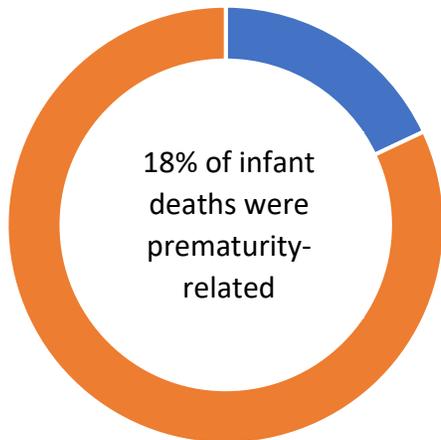
Charts and Data Takeaways: Preterm Birth and Preterm Related Mortality

Percent of Preterm births (<37 weeks gestation) by Race/Ethnicity



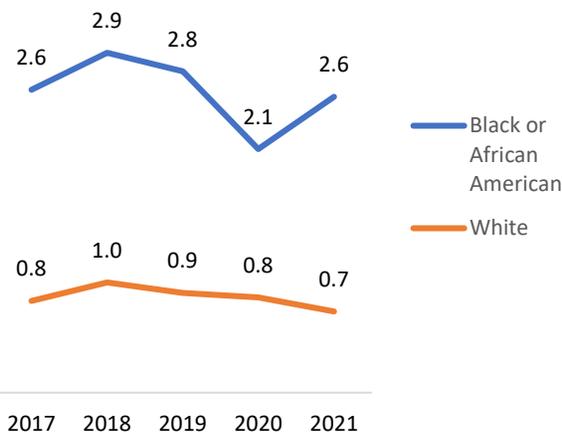
Source: National Vital Statistics System, Pennsylvania, 2020

Prematurity-Related Deaths, Pennsylvania, 2020



Source: Pennsylvania Death Certificate Dataset, 2020

Prematurity-Related Deaths Among Black vs White Infants (Death Rate per 1,000)



Source: CDC WONDER Online Database, Linked Birth/Infant Death Records, 2017-2021



Preterm birth trends have remained relatively flat over the last decade, **9.8% of births in Pennsylvania were preterm as of 2021**¹⁴.



In 2020, **preterm births were most prevalent among people aged 35 or older (11.3%) or among people aged 19 or less (10.2%)**⁸.



Preterm births were more prevalent among those covered by **Medicaid (11.9%) or other public insurance (12.7%)**⁸.



Recent data from 2020-2022 indicates **the leading cause of death among infants in Pennsylvania is extreme immaturity (ICD-10 P072)**⁸.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

SUID and Sleep-Related Deaths



What is SUID and Sleep-Related Deaths:

Sudden Unexpected Infant Death (SUID): An umbrella category that describes all sudden, unexpected infant deaths in the sleeping environment—from known causes, such as accidental suffocation or strangulation on the sleeping environment, from unknown and ill-defined causes and from sudden infant death. The different types of SUIDs are not interchangeable¹.

- *Accidental suffocation or strangulation in the sleeping environment* is a type of SUID that occurs when an object interferes with an infant's breathing, or an infant becomes trapped between two objects during sleep¹.
- *Unknown and ill-defined causes* is a type of SUID in which possible causes are undetermined and cannot be ruled out¹.
- *Sudden infant death syndrome (SIDS)* is a type of SUID that, even after a full investigation including a complete autopsy, examination of the death scene, and a review of the clinical history doesn't have a known cause. All possible causes have been ruled out¹.

Why addressing SUID and Sleep-Related Deaths is important:

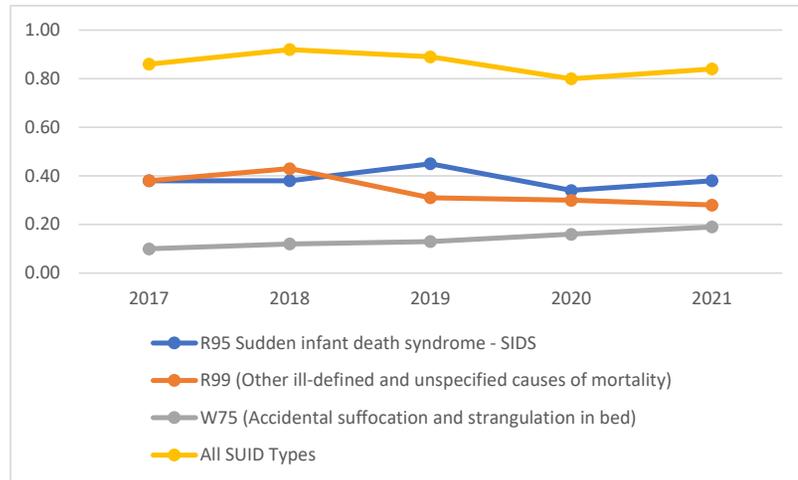
- In Pennsylvania sudden infant death syndrome and other ill-defined and unknown causes of mortality are two of the top five underlying causes of infant mortality².
- Sleep-related infant deaths, account for a large share of infant deaths after the first month of life. 90% of SUID cases happen before the child reaches 6 months old, with the largest portion of cases occurring between months 1 and 4³.
- Unsafe sleep practices increase the risk of SUID⁴.
- Safe sleep practices are modifiable risk factors that can help to prevent SUID⁴.

Factors Influencing the Issue:

- In addition to improper/unsafe infant sleeping conditions, preterm birth and low birth weight, parental substance use (including alcohol use and smoking), and lack of access to prenatal care, have been reported to increase the risk of SUID. Social inequities and structural and environmental factors like poverty, racial discrimination, and access to healthcare, may contribute to infant vulnerability^{5,6}.
- Families of color, families with a head of household with a high school education or less, families with no working members, and families that rented their homes were more likely to be living in poverty in Pennsylvania⁷. SUID rates are highest among Black infants, among infants of birthing people with lower educational attainment, and among infants of birthing people covered by Medicaid².
- Underlying social determinants of health including community, societal, and structural factors (i.e., cultural/family tradition, access to childcare, and financial and emotional stressors) resulting from inequitable access to economic, social, and educational resources disproportionately impact Black families and families of low socioeconomic status and may influence infant sleep practice^{8,9,10,11}.

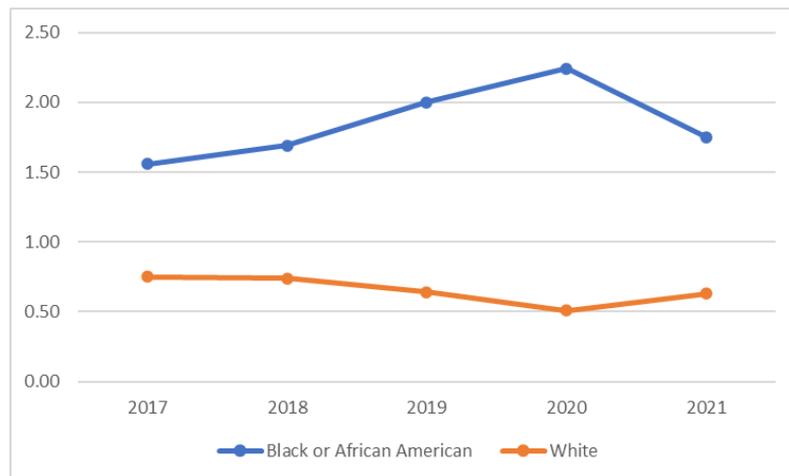
Charts and Data Takeaways:

SUID Rates by Cause of Death



Source: CDC WONDER 2017-2021

SUID Rates by Race



Source: CDC WONDER 2017-2021



The percentage of infants placed to sleep on their backs **has decreased slightly from 83.1% in 2018 to 81.6% in 2021¹².**



Over 50% of Pa. SUID cases list other ill-defined and unspecified causes and accidental suffocation and strangulation in bed as the cause of death¹³.



The percent of infants **placed to sleep on a separate sleep surface** had **significantly increased** from 31.5% in 2017 to a five-year high of 42.6% in 2021¹².



The following data are based on Pennsylvania child death review (CDR) data¹³:

- Of the total SUID 2021 deaths (ICD-10 codes listed as R99, R95 and W75), local CDR teams reviewed 52.7% (59).
- Unsafe sleep factors were present in 56 (94.9%) of the reviewed SUID deaths. Unsafe sleep factors include unsafe sleep surfaces (couches, adult beds, car seats, etc.) and/or items in the babies sleep area such as blankets, pillows toys, or other humans and/or animals.
- A safe place for the infant to sleep was available in 38 (64.4%) of the reviewed SUID deaths.

Child Mortality

What is Child Mortality:

Child Mortality refers to the death of a child who is 21 years of age and younger¹.² The leading cause of child mortality among children ages 1 to 9 is **unintentional injury** (no intent to do harm or accident)³, both nationally and in Pennsylvania⁴. Child deaths may be also categorized as **intentional**, and would include deaths involving bodily force or weapons, such as assaults or homicides, and suicide².

The leading causes of death among children in Pennsylvania from 2018 to 2021 were⁴:

Ages 1 to 4

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

Ages 5 to 9

- 1) Accidents and unintentional injuries
- 2) Cancer
- 3) Assault or homicide

Why addressing Child Mortality is important:

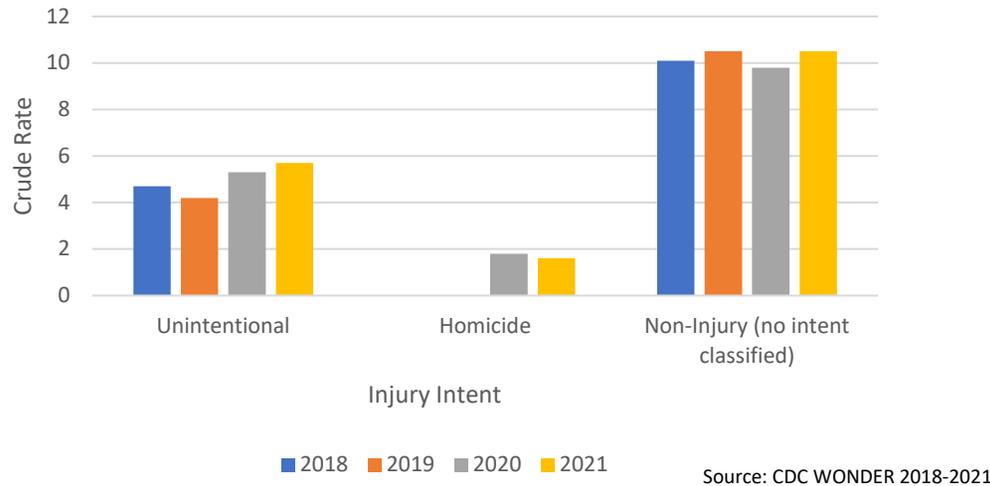
- To enable children to reach their full potential, it is important to promote physical, mental, and emotional well-being while also addressing factors in the environment in which children live and play⁵.
- For every child death, there are an estimated 25 non-fatal hospitalizations, representing a significant source of disability with lifelong mental, physical, and financial impact. Reducing the burden of nonfatal injury can greatly improve the life course trajectory of children resulting in improved quality of life and cost savings¹.
- Unintentional deaths are largely preventable³.
- Medicine and public health have made remarkable progress in lowering pediatric mortality rates, but the lives they have saved are now endangered by manmade pathogens. Nationally, increasing injury rates (including intentional and unintentional) are contributing to increasing overall child mortality rates, the largest such increase in recent memory⁶.

Factors Influencing the Issue:

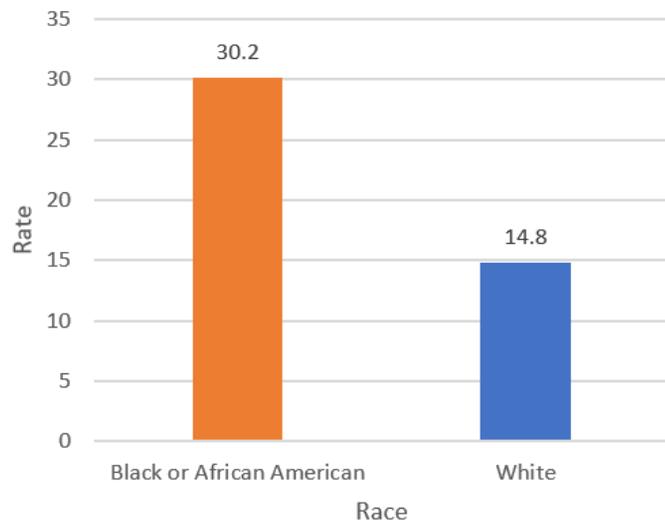
- The racial disparity in child mortality in the United States has persisted for decades⁷. Existing literature on the racial disparity in child fatality suggests that differences by race can be attributed to environmental and social inequities that exist because of structural racism and bias⁸. This may include issues accessing to safe, stable, and affordable housing and neighborhood conditions driven in part by current and historical discriminatory policies and practices like redlining and community disinvestment⁹.
- Firearm-related injuries and deaths, and child maltreatment and abuse continue to impact children, families, and both urban and rural Pennsylvania communities. Risk factors may include poverty, behavioral health challenges, family separation, community violence, and state gun laws¹⁰.

Charts and Data Takeaways:

Children Ages 1-9 years Death by Mechanism of Injury, Rates per 100,000



Children Ages 1-9 years Unintentional Injury Death, Rates per 100,000 by Race



Unintentional Injury Subtype (rate per 100,000)

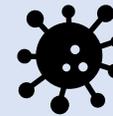
Black or African American
 Transport Accidents- 2.6
 Non Transport Accidents- 5.6

White
 Transport Accidents- 1.5
 Non Transport Accidents- 3.0

Source: CDC WONDER 2018-2021



Although the risk of death for children declines sharply beyond infancy, there were still **over 6,000 deaths among U.S. children ages 1 through 9** in 2021. The child mortality rate significantly also increased from 2020 to 2021¹.



COVID-19 was the **sixth leading cause of death among children ages 1 through 9** in 2021⁴.



Three-year estimates of child mortality stratified by demographic characteristics suggest that the rate of child **mortality is twice as high** among children between the **ages of 1 and 4** (24.0 deaths per 100,000) as compared to children between the **ages of 5 and 9** (12.0 deaths per 100,000)⁴.



When evaluating the rates by sex, the **mortality rate** appears to be **higher among male children** between the ages of 1 and 9 (20.3 deaths per 100,000) as compared to female children (14.0 deaths per 100,000)⁴.



Disparities by race/ethnicity also exist as the rate of child **mortality is over two times higher** among **non-Hispanic Black children** (34.7 deaths per 100,000) as compared to children of another race/ethnicity (16.2 non-Hispanic multiple race; 16.0 Hispanic; 14.4 non-Hispanic white, 7.4 non-Hispanic Asian)⁴.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Early Childhood Development and Protective Factors

What is Early Childhood Development and Protective Factors:

Early Childhood Development is the period of rapid physical, psychological and social growth and change that begins before birth and extends into early childhood. It can include many types of development including physical, cognitive, language and communication, and social and emotional¹.

Protective Factors are conditions or attributes in individuals, families, or the larger society that, when present, mitigate, or eliminate risk factors in families and communities and increase the health and wellbeing of children and families. They are usually grouped into six categories: *nurturing and attachment; knowledge of parenting and child development; parental resilience; social connections; concrete support for parents and caregivers; and social and emotional competence of children*².

- **Risk Factors** are variables that increase the likelihood of unwanted outcomes. Examples include poverty, parental depression, toxic parental stress, family conflict or violence, emotional neglect, and alcohol and other drug use in pregnancy³.

Why addressing Early Childhood Development and Protective Factors is important:

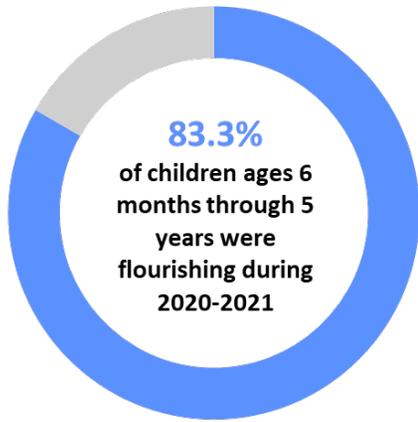
- A child's emotional growth and their ability to form social connections with other people begins during infancy⁴.
- Existing research suggests that children with a strong parent-child relationship early in life are more likely to experience positive physical and mental health outcomes later in life⁴.
- Development of healthy social and emotional behaviors in early childhood may prevent mental health problems and challenges during childhood and adolescence⁴.

Factors Influencing the Issue:

- Resilient families, or those that talk together about what to do when facing problems, work together to solve them, have strengths to draw on, and stay hopeful in difficult times, were more likely to report flourishing for their child. Children living in families with higher levels of resilience and connection are much more likely to flourish. This is true for children across levels of household income, health status and exposure to adverse childhood experiences⁵.
- Early childhood development and education programs can also help reduce educational gaps. However, recent studies have found Black children in Pennsylvania are less likely to be enrolled in high-quality preschool programs than white children. The researchers theorized that, among other factors, a lack of public investment in Black communities makes it difficult for preschool providers to operate, meet the performance standards - some of which have been questioned or criticized for not being culturally sensitive - needed to earn a high quality rating, and participate in Pre-K Counts (PKC), PA's state-funded pre-kindergarten program⁶. However, PKC does not meet the needs of many working families as it does not provide full-day, or full-year care and Black parents of young children participate in the workforce at higher rates and are more likely to work nonstandard hours^{6,7}.
- When social determinants of health are addressed, they can serve as protective factors⁸.

Charts and Data Takeaways:

Flourishing among Children ages 6 months through 5 years



Note: Flourishing captures a child’s ability to cope with stressors and form healthy relationships. In children under the age of 5, characteristics of flourishing include curiosity, resilience, attachment to caregivers, and contentment with life.

Due to limited availability of data, it was not possible to look at flourishing solely among children ages 1-5 years.

Source: National Survey of Children’s Health, Pennsylvania 2020-2021

Approximately **8 of every 10 children in Pennsylvania between the ages of 6 months and 5 years were flourishing during 2020-2021⁹.**

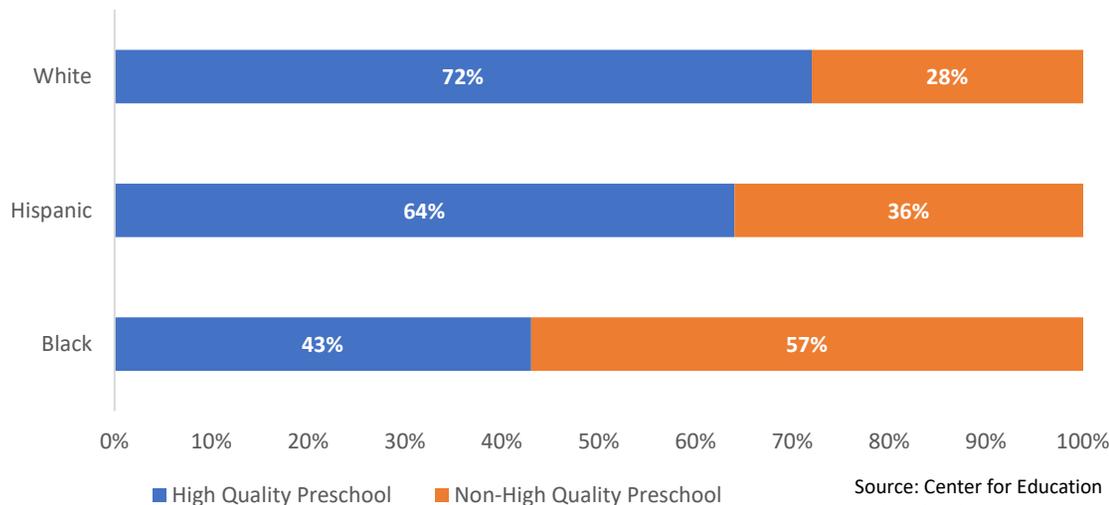


Data is limited but there is some suggestion that **children with special health care needs (CSHCN) are less likely to be flourishing than non-CSHCN⁹.**



Data is limited but there is some suggestion that **Hispanic children were less likely to be flourishing than White or Asian children⁹.**

Percent of Pennsylvania Children Enrolled in High Quality Preschool Programs by Race/Ethnicity, 2019



Source: Center for Education and Civil Rights, 2022



Black children are 1.67 times less likely to be enrolled in a high-quality preschool program than white children in Pennsylvania⁶.



Respondents to the Bureau of Family Health’s annual survey highlighted **increased parent/caregiver support and education on infant care, developmental milestones, and promoting infant health/well-being** as top unmet health needs in the infant health domain from 2021 through 2023¹⁰.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Oral Health

What is Oral Health:

Oral Health refers to the health of the teeth, gums, and the entire oral-facial system that allows us to smile, speak, and chew¹.

Access to routine preventative dental checkups and cleanings is a “vital component of overall health and oral health care remains an unmet health need for children. Insufficient access to oral health care and effective preventive services affects children’s health, education, and ability to prosper. To prevent tooth decay and oral infection, the American Academy of Pediatric Dentistry recommends preventive dental care for all children after the eruption of the first tooth or by 12 months of age, usually at intervals of every 6 months².”

Why addressing Oral Health is important:

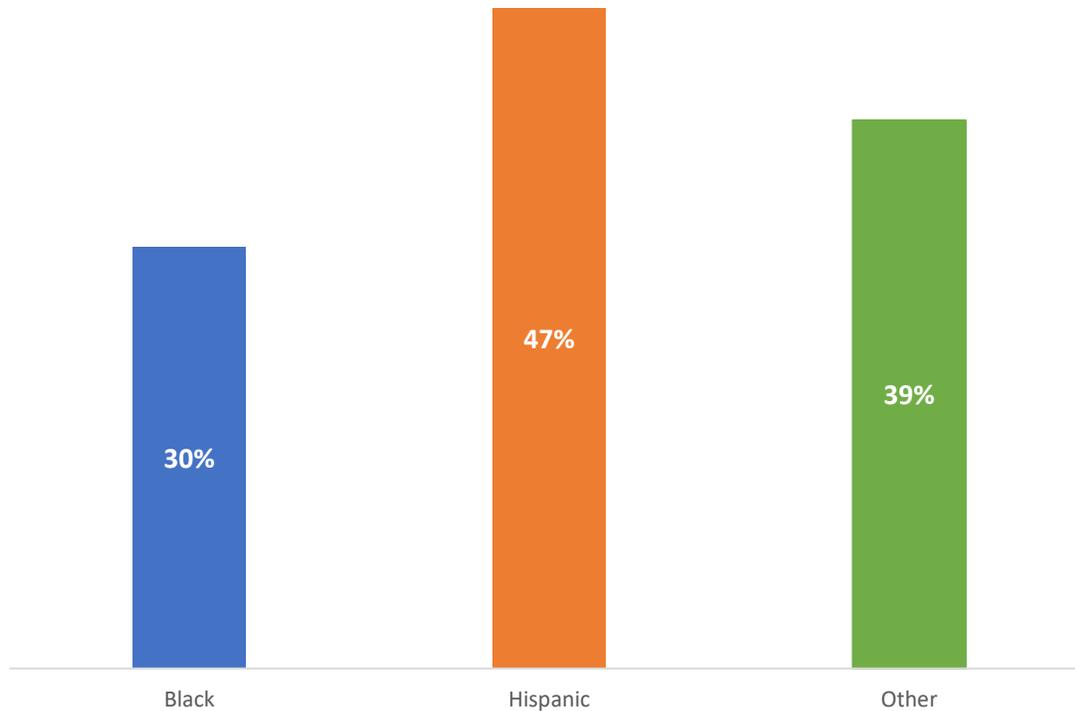
- Research suggests that the timing of a child’s first oral health examination/preventive dental visit likely impacts the development of cavities³.
- Much of early childhood tooth decay can be prevented by self-care, receiving professional dental care, and community-level interventions like water fluoridation⁴.
- Cavities are the most common chronic disease of childhood and left untreated can cause pain and infections that may lead to problems with eating, speaking, playing, and learning⁵.
- Oral health is a key indicator of overall health wellbeing, and quality of life⁶.

Factors Influencing the Issue:

- Many studies have shown an association between low socioeconomic status and the commonness of childhood dental issues or lack of access to preventive dental care which may be credited to social and structural determinants of health, dental health care that is separate from all other physical health care, food security and access to nutritious food, and community level access to fluoride^{7, 8}.
- Many children lack access to regular, quality dental care. In 2019, about half of the children enrolled in Medicaid did not see a dentist as only one-third of U.S. dentists accept public insurance^{9,10}. Also, in 2021 only 17.2% of Pennsylvania’s dental workforce was practicing in rural areas.¹¹
- Individual, including insurance type and receipt of topical fluoride and restorative procedures, and community-level factors, such as education attainment and the socioeconomic conditions of neighborhoods, accounted for substantial proportions of observed racial and ethnic disparities in the risk of tooth decay¹².

Charts and Data Takeaways:

Higher Risk of Tooth Decay Among Children, Ages 0-5, from Other Racial and Ethnic Groups as Compared to White Children



Source: Analysis of Race and Ethnicity, Socioeconomic Factors, and Tooth Decay Among US Children, Choi, White, Mertz, et al, 2023



For children aged 2 to 5 years, 17% of children from low-income households have untreated cavities in their primary teeth, 3 times the percentage of children from higher income households¹³.

By age 8, over half of children (52%) have had a cavity in their primary (baby) teeth¹⁴.



By ages 12 to 19, 23% of children from low-income families have untreated cavities in their permanent teeth, twice that of children from higher-income households¹³.

Children aged 6 to 19 years from low-income households are about 15% less likely to get sealants and twice as likely to have untreated cavities compared with children from higher-income households¹³.



The prevalence of tooth decay and cavities is higher among children with special health care needs (11.4%) as compared to children without (9.6%) and among children with Medicaid (17.7%) as compared to children with private insurance (5.4%)¹⁵.

Bullying and Violence Prevention

What is *Bullying and Violence Prevention*:

Bullying is any unwanted aggressive behavior(s) by another youth or group of youths, who are not siblings or current dating partners, that involves an observed or perceived power imbalance, and is repeated multiple times or is highly likely to be repeated. Bullying may inflict harm or distress on the targeted youth including physical, psychological, or educational harm¹.

- **Bullying Prevention** helps kids to understand bullying, teaching kids about bullying and how to safely stand up, showing them how to get help, listening and providing routine check-ups².

Youth Violence is the intentional use of physical force or power to threaten or harm others by young people. It can include fighting, bullying, threats with weapons, and gang-related violence. A young person can be involved with youth violence as a victim, offender, or witness³.

- **Youth Violence Prevention** uses strategies and approaches such as promoting family environments that support healthy development, providing quality education early in life, strengthening youth's skills, connecting youth to caring adults and activities, creating protective community environments, and intervening to lessen harms and prevent future risk⁴.

Why addressing *Bullying and Violence Prevention* is important:

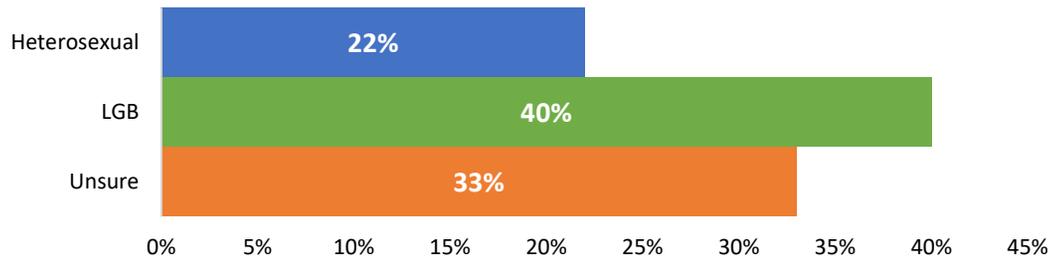
- Bullying and violence can have lasting effects on the physical, mental, and social health of young people. Bullying increases the risk for weapon carrying, fighting, dating violence, and suicide⁵. Youth who bully others are at increased risk for substance misuse, academic problems, and experiencing violence later in adolescence and adulthood¹.
- Youth violence is a leading cause of death and nonfatal injuries in the United States. Black or African American youth and young adults are at higher risk for the most physically harmful forms of violence (e.g., homicides, fights with injuries, aggravated assaults) compared with White youth and young adults⁶. Sexual minority adolescents are more likely to experience multiple forms of violence compared to their heterosexual peers³.
- Homicide is the third leading cause of death among persons aged 10 to 24 years and the leading cause of death for non-Hispanic Black or African American youth³.
- Medicine and public health have made remarkable progress in lowering pediatric mortality rates, but the lives they have saved are now endangered by manmade pathogens, such as bullets, drugs, and automobiles. Nationally, increasing injury rates (including intentional and unintentional) are contributing to increasing overall child mortality rates, the largest such increase in recent memory¹².

Factors Influencing the Issue:

- Children from abusive homes are more likely to bully as they have had aggression, violence, and manipulation modeled for them. Children who have poor communication skills or difficulty managing their emotions are more likely to bully⁷.
- Studies have shown that, in addition to being bullied for their sexual and/or gender identity, sexual minority youth are more likely to be bullied for other parts of their identity such as race or weight than their straight cisgender peers⁸.
- Among many other factors, long-time structural disinvestment, which describes when a city or town decides to neglect if not wholly abandon an area and not provide resources for revitalization or improvement, and institutional racism contribute to conditions in which community violence including gun violence is more likely to happen⁹. Children who grow up and live in environments with limited social, educational, and economic opportunities and where violence, racism, and community and domestic instability are daily stressors are at increased risk of multiple forms of violence⁵.

Charts and Data Takeaways:

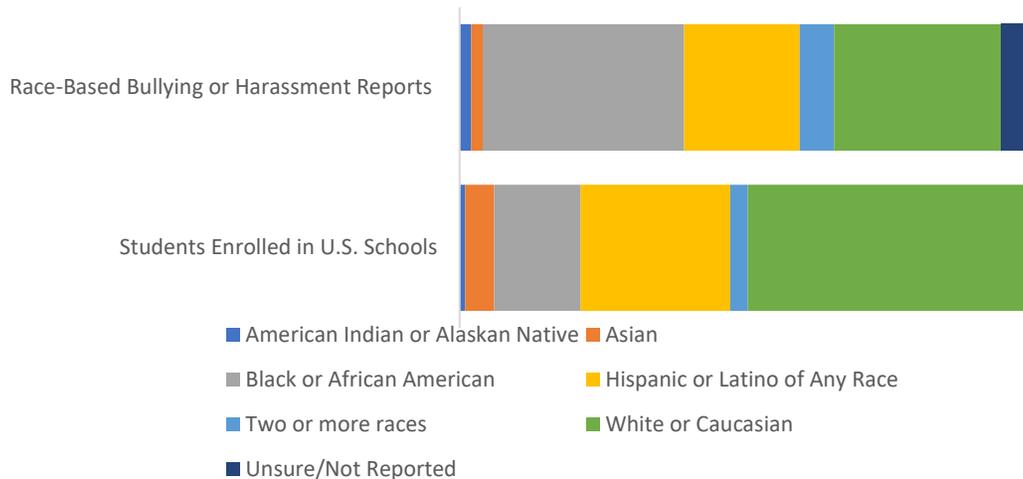
Distribution of Bullying Incidents Among U.S. High Schoolers by Sexual Identity of Victims, 2019



Source: Youth Risk Behavior Survey, 2019

Note: the 'Unsure' category includes students who were unsure of their identity, those who did not feel comfortable answering the question, and those who did not understand the question.

Comparison Between Percentage of Students Enrolled in U.S. Schools and Race-Based Bullying or Harassment Reports



Source: Teen Talk Recommendations: J. Shapiro, 2019

About 1 in 5 high school students reported being bullied on school property. More than 1 in 6 high school students reported being bullied electronically in the last year¹.



The number of young people who are treated for nonfatal physical assault-related injuries in emergency departments in the United States is more than 115 times higher than the number killed¹⁰.



Many risks for violence, such as child abuse and neglect, academic problems, and poor supervision and management of children's behavior, also emerge early and heighten the likelihood for violence during adolescence and young adulthood¹⁰.



Bullied students reported that bullying occurred in the following places: the hallway or stairwell at school (43%), inside the classroom (42%), in the cafeteria (27%), outside on school grounds (22%), online or by text (15%), in the bathroom or locker room (12%), and on the school bus (8%)¹¹.

Mental Health and Suicide Prevention

What is Mental Health and Suicide Prevention:

Mental Health refers to a person's emotional, cognitive, and psychological wellbeing¹. Mental disorders among children are described as serious changes in the way children typically learn, behave, or handle their emotions, which cause distress and problems getting through the day².

Suicide is death caused by injuring oneself with the intent to die. Suicide and suicidal ideation often indicate mental health problems and stressful or traumatic life events^{3,4,5}.

- **Suicidal ideation**, or suicidal thoughts or ideas, is a broad term used to describe a range of thoughts, wishes, and preoccupations with death and suicide⁶.

Why addressing Mental Health and Suicide Prevention is important:

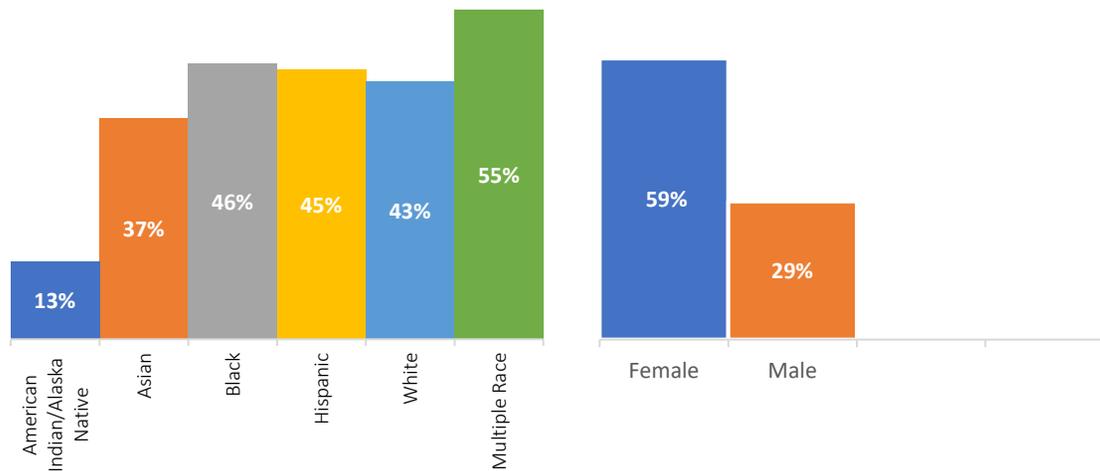
- Nearly all indicators of poor mental health and suicidal thoughts and behaviors increased from 2011 to 2021⁴.
- The percentage of U.S. students who experienced persistent feelings of sadness or hopelessness, seriously considered attempting suicide, made a suicide plan, and attempted suicide increased⁴.
- In 2019, suicide was the second most common cause of death for adolescents ages 15 through 19 years⁷.
- Poor mental health can result in serious negative outcomes for the health and development of adolescents, which can last into adulthood⁸.

Factors Influencing the Issue:

- Only 20% of children with mental, emotional, or behavioral disorders receive care from a specialized mental health care provider. This may be due to several factors including a lack of providers in their area, high costs, lack of insurance coverage, and time and effort required for parents to find and access care. Adequate insurance and access to a patient-centered medical home may improve mental health treatment⁹.
- Partner reports and stakeholders highlighted the role of trauma and systematic marginalization and discrimination as risk factors for poor mental health and highlighted specific populations disproportionately impacted including youth identifying as female, LGBTQ+, Black, or Hispanic^{10,11}. Persistent feelings of sadness or hopelessness were found to be more common among LGBTQ+ students, female students, and students identifying as multiple races⁵. Black students were more likely to attempt suicide than students of other races and ethnicities⁴.

Charts and Data Takeaways:

Pennsylvania High School Students Reporting Feeling Sad or Hopeless



Data suggest that the **prevalence of depression and anxiety have increased in recent years**, mirroring increasing national trends in adolescent depression and anxiety between 2016 and 2020¹².

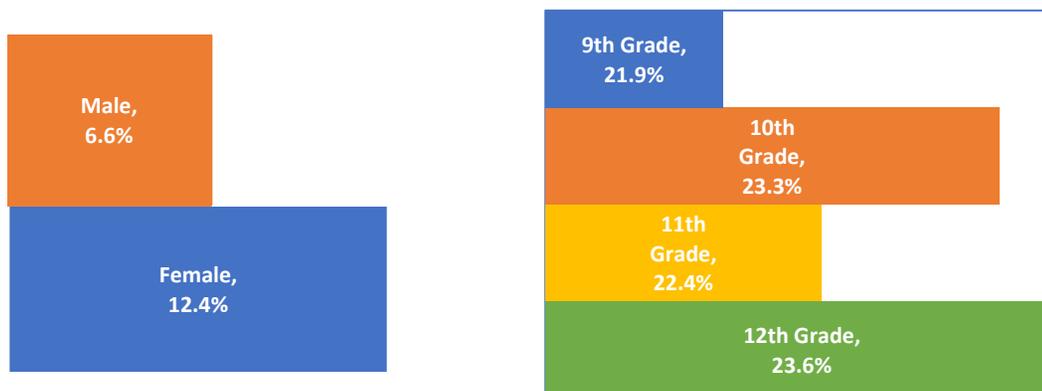


The percentage of students across every racial and ethnic group **who felt persistently sad or hopeless increased**¹².



Nearly 60% of female students and nearly 70% of LGBQ+ students **experienced persistent feelings of sadness or hopelessness**¹².

Distribution Among Pennsylvania High School Students Who Reported Actually Attempting Suicide



The percentage of U.S. female students **who seriously considered attempting suicide, made a suicide plan, and attempted suicide increased** from 2011 to 2021¹².



10% of U.S. female students and more than 20% of LGBQ+ students **attempted suicide**. 9.5% of PA high school students reported actually attempting suicide¹².

Source: Pennsylvania, High School Youth Risk Behavior Survey, 2021
Question: Seriously Considered Attempting Suicide (during the 12 months before the survey)

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Sexual and Reproductive Health

What is Sexual and Reproductive Health:

Sexual Health: is a state of physical, emotional, mental, and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence¹.

Reproductive Health is a state of complete physical, mental, and social wellbeing in all matters relating to the reproductive system².

Why addressing Sexual and Reproductive Health is important:

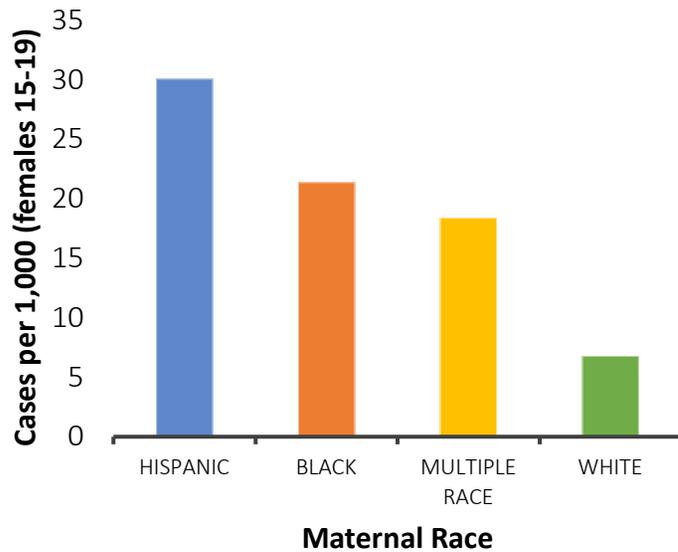
- Adolescent pregnancy and childbearing have substantial social and economic costs for both adolescents and their children³. Birth rates for Hispanic, non-Hispanic Black, and multiple race adolescents are approximately double that of non-Hispanic white adolescents both nationally and in Pennsylvania⁴.
- Better information and improved access to services help youth—with the support of their parents and caregivers—make informed decisions about their sexual and reproductive health and wellbeing⁵. Research shows that abstinence-plus programs* have an impact on sexual behavior, including HIV prevention, increased condom use, fewer sexual partners, and a delayed start of sexual activity⁶.
*a program encouraging abstinence that also includes information on contraception and resources for safer sex practices⁷.

Factors Influencing the Issue:

- Living in an area with high rates of housing instability, segregation, and a lack of resources has been linked to increased risk of teen pregnancy⁸. For Black female adolescents in poorer areas, studies have shown that parental influence, peer influence, social messages, substance use including alcohol, and pregnancy desire, as well as lack of information about sex are risk factors for early pregnancy⁹.
- Many sexual and reproductive health programs may not provide lesbian, bisexual, gay, transgender, and queer youth with accurate, comprehensive information on safer sex practices for them. Youth identifying as gay, lesbian, or bisexual or reporting same-sex attraction or sexual partners are at higher risk of negative health behaviors and outcomes, including HIV, other sexually transmitted diseases (STD), pregnancy, and related risky sexual behaviors¹⁰. Also, research has shown, that as adolescence is a time of self-exploration including sexual identity, adolescents may not always behave in ways consistent with their sexual identity or take appropriate measures to reduce risk. For example, an increased risk of pregnancy was noted for adolescents identifying as lesbian as they were less likely to use condoms when engaging in sex with opposite sex partners¹¹.
- Adolescents may experience period poverty, or inadequate access to menstrual hygiene tools and education including sanitary products, washing facilities, and waste management. Menstrual products are expensive in the U.S. and surveys have shown that 1 in 5 menstruating teens struggled to afford menstrual products, and 4 in 5 either missed or knew someone who missed class because they did not have access to period products. Government benefits, such as SNAP and WIC, cannot be used to buy these supplies¹².

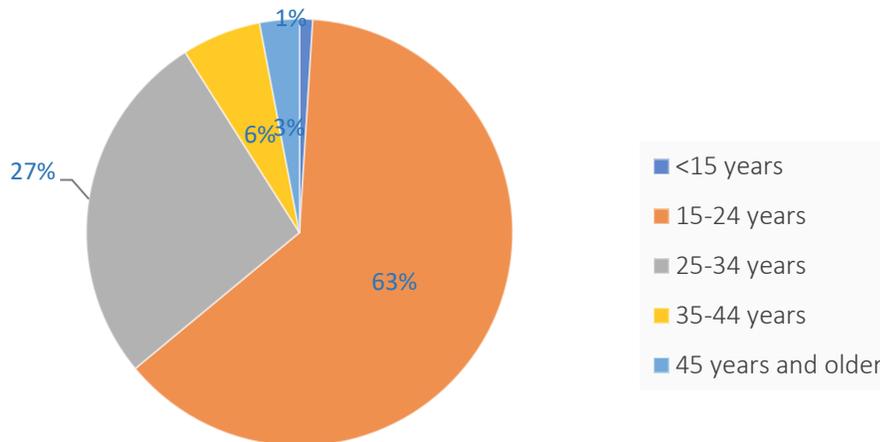
Charts and Data Takeaways:

Pennsylvania Teen Birth Rate by Race/Ethnicity, 2021



Source: National Vital Statistics System, 2021

Pennsylvania Chlamydia Distribution by Age Group, 2021



Source: Pennsylvania Department of Health, Bureau of Communicable Diseases



The teen birth rate is 2 to 3x higher among Hispanic, non-Hispanic Black, and non-Hispanic multiple race youth as compared to white youth⁴



Respondents to the Bureau of Family Health's annual survey identified **improved access to sexual health services, education, and access to contraception** as one of the top unmet needs in 2021 and 2022¹³.



A 2023 youth focus group identified **sexual activity and sexual dating violence** as a top concern¹⁴.



15-24 year olds account for **about half of all new STDs** despite only being approximately one-quarter of the sexually active population¹⁵.



The National Youth Risk Behavior Data Summary and Trends report **highlights a need for increased condom use and testing for HIV and sexually transmitted infection and disease** among adolescents¹⁶.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Domain: Children and Youth with Special Health Care Needs (CYSHCN) Provider Access, Care Coordination, and Navigation

What is Provider Access, Care Coordination, and Navigation:

Provider Access involves 4 criteria: *coverage*, or the service is paid for; *service*, or the transaction or good meets the need of the child; *timeliness*, or the service is provided when needed; and, *capability*, or the workforce is effective, qualified, and culturally competent¹.

Care Coordination involves deliberately organizing patient care activities and sharing information among all the participants concerned with a patient's care to achieve safer, more effective care².

Navigation guides families through and around barriers in the health care system. Navigators can provide psychosocial support, help coordinate services, provide education related to a child's health care needs, and ease challenges³.

A Well-Functioning System for CYSHCN is one in which families of CYSHCN are partners in decision-making at all levels; CYSHCN receive coordinated, ongoing comprehensive care within a medical home; families of CYSHCN have adequate private and/or public insurance; children are screened early and continuously for special health care needs; services for CYSHCN are organized so families can use them easily and are satisfied with the services they receive; and youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence⁴.

Medical Home is a model of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. It is not a physical place, but an approach⁵.

Why addressing Provider Access, Care Coordination, and Navigation is important:

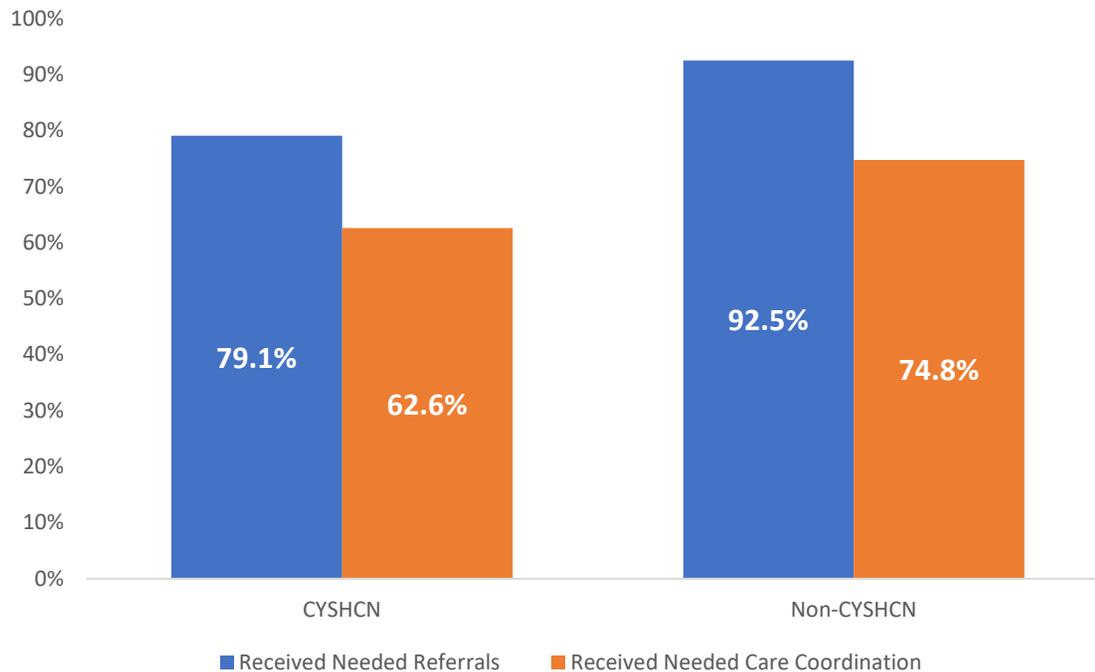
- CYSHCN are more likely than non-CYSHCN to have unmet health care needs, which is needing but being unable to receive health care for any reason⁶.
- CYSHCN and their families may need to access a range of public and private services at various times in their lives. Finding, accessing, and receiving multiple services and providers can be difficult for families to manage in a fragmented health care system³.
- Access to services is built on relationships instead of a series of transactions. Opportunities for innovation include creating a single point of service entry; determining services based on need instead of diagnosis; and emphasizing service continuity, transition, and a place-based approach¹.
- CYSHCN are less likely than non-CYSHCN to have effective care coordination⁷.

Factors Influencing the Issue:

- CYSHCN are more severely impacted by the adverse effects of social determinants of health and inequities. Navigating a poorly coordinated system is harder for those families who struggle with poverty, lack of food, housing, transportation, and/or racism. For CYSHCN who have more complex needs, family members frequently are called on to serve as caregivers and care coordinators⁴.
- The systems that serve CYSHCN are not designed to address health equity and can make disparities worse in both the short and long term. For example, poor children, minoritized children, and CYSHCN are more commonly covered by Medicaid and may have a harder time getting appointments to see their pediatrician due to different reimbursement policies for Medicaid versus private insurance⁸.

Charts and Data Takeaways:

Percentage of Children Ages 0-17 Who Reported No Difficulties Receiving Needed Referrals and Received Needed Care Coordination



Source: National Survey of Children's Health 2020-2021



More than **82% of CYSHCN** ages 0-17 in Pennsylvania did not have access to a well-functioning system of services⁴.



CYSHCN are less likely than children without special health care needs to obtain **needed referrals, as well as needed care coordination**⁸.



Among CYSHCN who experienced an unmet health need, the most commonly reported reasons were related to **cost and appointment availability**⁶.



45.6% of CYSHCN ages 0 through 17 in Pennsylvania receive care that meets medical home criteria, compared to **48.8% of children without special health care needs**⁸.



Respondents to the Title V Public Input survey highlighted the need for **care navigators**, the challenge of **siloe d services and waitlists** associated with referrals and specialty care, and a need for **improved coordination between healthcare, school, and social service systems**⁹.

Safe Relationships, Bullying, and Sexual/Reproductive Health

What are Safe Relationships, Bullying, and Sexual/Reproductive Health:

Safe Relationships are ones where youth can safely feel and express respect for themselves and others. Youth form many different relationships during childhood and adolescence including relationships with caregivers and parents, romantic/dating relationships, and friendships. Safe relationships are built on mutual trust, respect, communication, and consent¹.

Bullying is any unwanted aggressive behavior(s) by another youth or group of youths, who are not siblings or current dating partners, that involves an observed or perceived power imbalance, and is repeated multiple times or is highly likely to be repeated. Bullying may inflict harm or distress on the targeted youth including physical, psychological, or educational harm².

Sexual/Reproductive Health is a state of physical, emotional, mental, and social wellbeing in relation to sexuality and/or the reproductive system; it is not merely the absence of disease, dysfunction, or infirmity. Sexual/reproductive health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence³.

Why addressing Safe Relationships, Bullying, and Sexual/Reproductive Health is important:

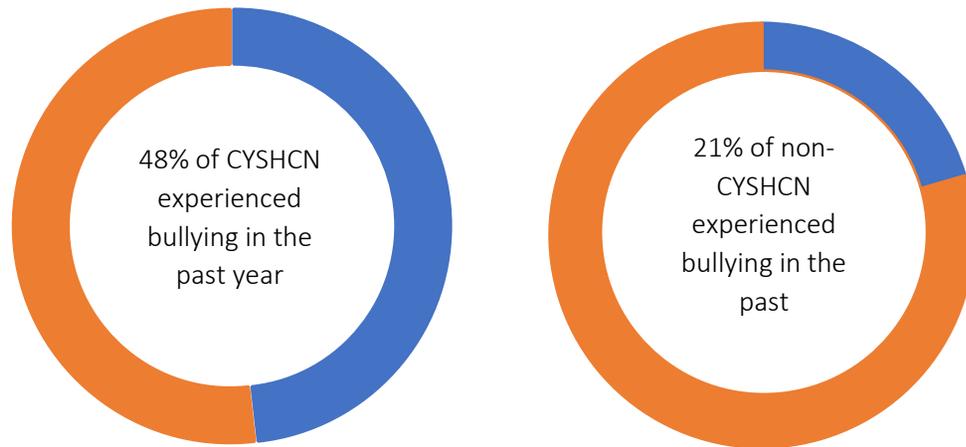
- Bullying and violence can have lasting effects on the physical, mental, and social health of young people⁴.
- Better information and improved access to services help youth—with the support of their parents and caregivers—make informed decisions about their sexual and reproductive health and wellbeing⁵.
- Research shows that abstinence-plus programs (programs that encourage abstinence and provide information on contraception and safer sex practices) have an impact on sexual behavior, including HIV prevention, increased condom use, fewer sexual partners, and a delayed start of sexual activity⁶.

Factors Influencing the Issue:

- CYSHCN are less likely to receive education or services related to safe interpersonal relationships or sexual/reproductive health and may be at increased risk of intimate partner violence or other forms of relationship abuse or exploitation than their peers^{7,8,9,10}. Disabled people are particularly vulnerable to victimization for a variety of reasons, including to reliance on caregivers, limited transportation options, limited access to Sign Language interpreters and assistive devices, and isolation from the community. These same factors may make reporting and getting help for abuse and other crimes difficult as well¹¹.
- CYSHCN are twice as likely to experience bullying than other children in Pennsylvania¹².
- Pregnancy and STI prevention education is not a standard part of the special education curriculum, especially for youth with more severe disabilities, and students with disabilities who are in mainstream classes are often pulled out of pregnancy prevention education either to receive other services or because it is thought that they will be upset, confused, and/or disruptive. Thus, many do not receive any pregnancy prevention education or, if they do, broad coverage of sexual health topics is scant¹³.

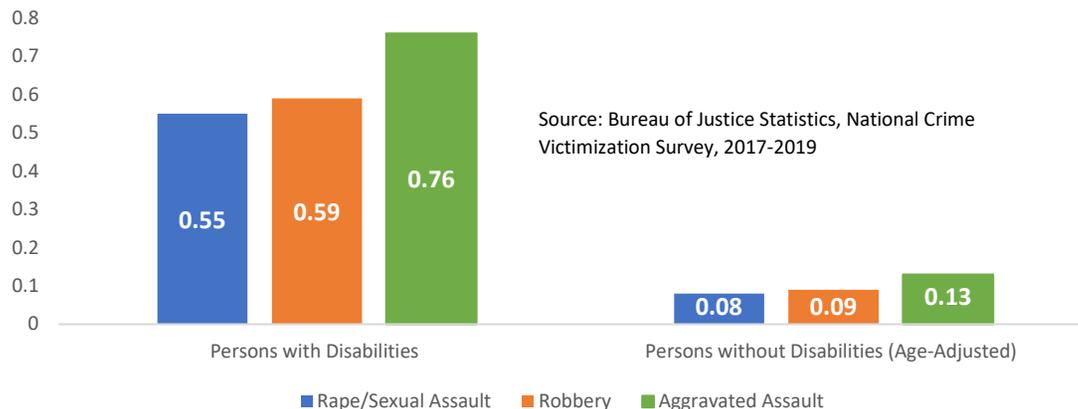
Charts and Data Takeaways:

Bullying among Youth ages 12-17 with and without Special Health Care Needs



Source: National Survey of Children's Health, Pennsylvania 2020-2021

Rate of Violent Victimization Against Persons 12 Years of Age or Older, By Type of Crime and Disability Status, 2017-2019



Source: Bureau of Justice Statistics, National Crime Victimization Survey, 2017-2019



Almost 1 of every 2 youth ages 12 to 17 with special health care needs experienced bullying in the past year; by comparison, 1 of every 5 youth without special health care needs experienced bullying in the past year during 2020-2021¹²

During a focus group held by the Bureau of Family Health in 2022¹⁴:



20% of participating children and youth with special health care needs **indicated that they needed help handling bullying.**



50% of participants **indicated that support and services related to safe relationships and reproductive health were needed and important.**



National data suggest that **adults with a disability are at increased risk of experiencing sexual violence or intimate partner violence including control of reproductive and sexual health, stalking, or psychological aggression**¹⁵.

Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

Support for Families and Caregivers of CYSHCN

What is Support for Families and Caregivers of CYSHCN:

Caregiver of CYSHCN: Caregiving encompasses the nurturing, tasks, resources, and services that meet the day-to-day needs of CYSHCN at home. By definition, caregiving occurs outside of professional settings and is driven by the families of CYSHCN¹. Caregivers of CYSHCN may need family support services such as care coordination, respite services, mental health care, and peer support².

Respite care is short-term care that is provided to a disabled child to allow the primary caregiver, who is usually a parent, time off and help ease the caregiver's stress³.

Why addressing Support for Families and Caregivers of CYSHCN is important:

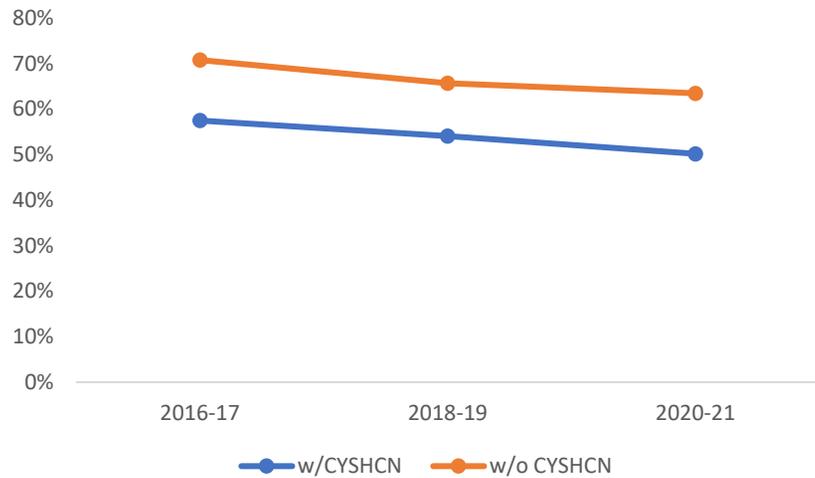
- Family caregivers, by default, play a central, distinguishable role in caring for CYSHCN¹.
- Caregiver's lives can be impacted in many ways such as financially, including the ability to work; physically, including the ability to maintain their own health; mentally including feelings of stress, loss, and grief; and in their relationships with others, including lack of social support, and strained marriages^{4,5}.
- Indirect evidence suggests that poor caregiver health may contribute to recurrent hospitalizations and out-of-home placements for children with chronic conditions and disabilities⁶.

Factors Influencing the Issue:

- Parents and family members of CYSHCN are more likely than parents and family members of children without special health care needs to leave a job, take a leave of absence, or cut down on hours worked due to their child's health or health condition⁷. Caregivers of CYSHCN do not receive the training or ongoing support they need; ultimately, only a minority of caregivers access resources available to them. This is due to several factors including whether the individual is identified as a caregiver, awareness of supports, eligibility criteria, the application and enrollment process, and the contingency of services being available⁸.
- CYSHCN are more severely impacted by the adverse effects of social determinants of health and inequities⁹.
- Access to services for CYSHCN must include a system serving CYSHCN and their families that is designed to be proactive and equitable, supporting the life course, and incorporating the lived experience¹⁰.

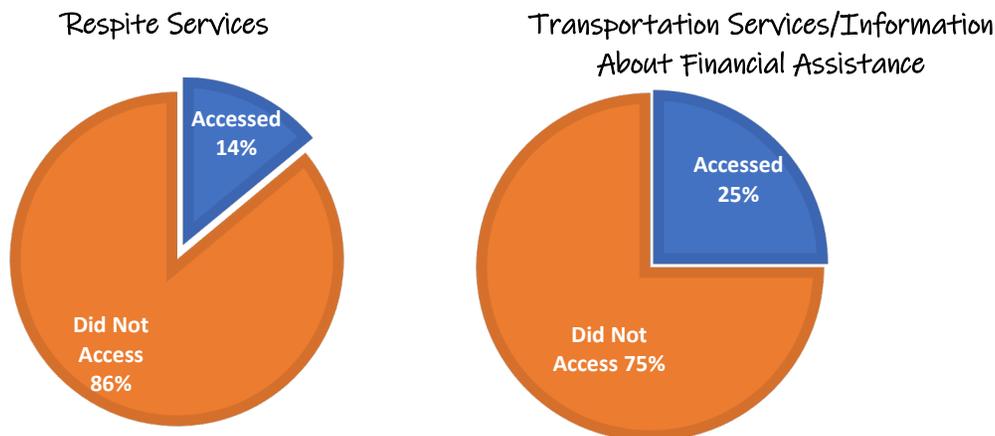
Charts and Data Takeaways:

Percentage of CYSHCN with a Parent Who Indicated They were Coping Very Well with the Day-to-Day Demands of Parenting:



Source: National Survey of Children's Health, 2016-2021

Caregiver Access of Supportive Services



Source: National Alliance for Caregiving & AARP Public Policy Institute, 2020
 Note: These charts show access of supportive services for those caregiving for children as well as adults.



Parents of CYSHCN were **less likely (than parents without CYSHCN)** to indicate that they were coping very well with the day-to-day demands of parenting⁷.



Respondents to the Department's 2022 and 2023 Title V Public Input Survey indicated that **families need additional support with basic needs like housing, transportation, and employment**¹¹.



In a study of the health implications of long-term disabilities, **41% of the caregivers reported that their health had worsened over the past year**. The changes were attributed to a lack of time, lack of control, and decreased (psychosocial) energy⁶.

According to a 2020 AARP report, only **14% of caregivers**, for adults as well as children, accessed available **respite services** and only **25% of caregivers** accessed **transportation services**, or information about **financial assistance**¹².



Questions? Please contact the Bureau of Family Health at the following email address: ra-dhpatitlev@pa.gov.

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