

2021 Pennsylvania Child Death Review Annual Report

Deaths Occurring in 2019

**Bureau of Family Health
Division of Bureau
Operations**

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pennsylvania
DEPARTMENT OF HEALTH

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Acknowledgements

The 2021 Child Death Review (CDR) Annual Report is a publication of the Pennsylvania Department of Health under the requirements of Act 87 of 2008.

The CDR process begins when the Department of Health, Bureau of Health Statistics and Registries (BHSR), provides vital statistics information to local CDR teams on a quarterly basis. Without BHSR's assistance, local teams would not receive the information as quickly and their support is greatly appreciated.

The data collected by the local CDR teams are housed in the web-based National Child Death Review Case Reporting System (NCFRP-CRS). This data system was developed in collaboration with the National Center for Fatality Review and Prevention and state CDR programs and was supported, in part, by a grant from the Maternal and Child Health (MCH) Bureau (Title V, Social Security Act), Health Resources and Services Administration, U.S. Department of Health and Human Services. The National Center for Fatality Review and Prevention also graciously provides technical assistance to Pennsylvania. In addition, the Centers for Disease Control and Prevention (CDC) provides funding and assistance to the department to support the activities related to the Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Registries. This work is also supported with funding from the Title V Maternal and Child Health Services Block Grant.

This report presents information on the distribution and causes of child deaths in Pennsylvania and reflects information collected by the local teams during the CDR process. The CDR process and the data derived from it are the result of a collaboration between the department and local CDR teams. The local teams collaborate with their local prevention partners to develop programs, activities and education efforts aimed at preventing child deaths. The department would like to thank the statewide and local prevention partners for their assistance moving data into action.

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About This Report

The department would like to acknowledge the contribution of the local CDR teams and the state CDR team, without whom this data and the entire CDR program in Pennsylvania would not be possible. The data provided in this report are based on the year of death, not the year of review. It focuses on those child deaths occurring in 2019 and the reviews of those deaths. Primarily, the data outlined in this report were extracted from the NCFRP-CRS and supplemented by other sources where noted.

Introduction

The purpose of Pennsylvania's Child Death Review (CDR) Annual Report is twofold. The first is to summarize the findings from the reviews of child deaths and the second is to make recommendations about how to utilize those findings to inform prevention strategies and programming. This report highlights some of the prevention work accomplished locally and at the state level throughout the year. Pennsylvania's CDR Program continues to explore opportunities for supporting local teams in their work. The department recognizes the importance of evidence-based prevention strategies and the value of effective death reviews to inform those strategies. Through this program, deaths among Pennsylvania's children can be better understood and interventions designed to prevent future deaths can be identified.

The NCFRP-CRS is the primary source of data for the Pennsylvania CDR Annual Report. The data are based entirely on information collected and entered into the NCFRP-CRS by local CDR teams. The report also includes child mortality rates from the CDC's Wide-Ranging Online Data for Epidemiologic Research (CDC WONDER) for context and comparison.

An effective child death review requires participation and cooperation from agencies and individuals at a state and a local level. The review process is initiated when information collected from death certificates, birth certificates and traffic accident reports is compiled by department staff and securely transferred to local county teams on a quarterly basis. Local teams use this information to initiate collaborative, multidisciplinary reviews. The death review process includes gathering available information related to the child's death and is not limited to only those items contained within death certificates. This includes, among other data, information derived from law enforcement reports, coroner reports, children and youth services records, emergency medical services trip sheets, hospital records and traffic accident reports.

As with any team, the local CDR teams cycle through the stages of development for a variety of reasons. Act 87 of 2008 provides a mandate for establishment of child death review teams in each of Pennsylvania's 67 counties, and teams consist of professionals from organizations and local agencies. Local CDR teams do not have dedicated staff and operate with limited resources. Turnover of team members can mean that teams are frequently operating in the beginning stages of team development, which impacts the quality of the reviews and the completeness of the data collection and reporting. The Department of Health's Bureau of Family Health (BFH), provides training, support and technical assistance to all of Pennsylvania's local CDR teams.

Executive Summary

Data collected from reviews of child deaths occurring in 2019 are the basis for this report. Act 87 of 2008 defines a child as an individual 21 years of age and under. Reviews are conducted of children's deaths from birth through age 21 years. Overall, there were slightly fewer deaths of children in 2019 than in 2018. The BHSR data shows that there were 1,907 deaths of children in 2019, reflecting a 0.83% decrease from 1,923 deaths in 2018. Of the 1,907 deaths occurring in 2019, 824 (43.2%) were reviewed and entered in the NCFRP-CRS by local CDR teams. Of the 2018 deaths, 1,063 (55.3%) were reviewed and entered in the NCFRP-CRS by local CDR teams. Many teams were unable to complete a review of all children's deaths occurring in 2019 due to COVID-19 mitigation efforts which impacted the ability of teams to meet and some key team members capability to devote time and resources to CDR.

Race

Both the national rate and the Pennsylvania rate of Black or African American children's deaths saw an increase from 2018 to 2019. In Pennsylvania, the rate increased from 88.5 per 100,000 population in 2018 to 91.75 per 100,000 population in 2019. Nationally, for the same time period, the rate increased for Black or African American children from 88.6 per 100,000 to 90.2 per 100,000. Black or African American children continue to die at a rate nearly twice that of white children.

While the national rate remained relatively flat in 2019, the Pennsylvania rate saw a slight decrease in the rate of death for white children. The Pennsylvania rate was 44.8 per 100,000 population in 2019 compared to 46.5 per 100,000 population in 2018. In 2019, the national rate was 46.1 per 100,000 population and in 2018, the rate was 47.0 per 100,000 population.

The rate of death for Asian or Pacific Islander children residing in Pennsylvania decreased from 37.4 per 100,000 population in 2018 to 31.0 per 100,000 population in 2019. The national rate decreased in 2018 from 33.5 per 100,000 population to 31.9 per 100,000 population in 2019.

Age, Cause, and Manner

Data from CDC WONDER and BHSR shows that both nationally and in Pennsylvania, the largest rate of deaths by age group in 2019 is infants (children less than 1 year old). In Pennsylvania, the death rate of infants decreased from 594.3 per 100,000 in 2018 to 585.0 per 100,000 in 2019. Nearly half of the 2019 deaths reviewed were deaths among infants. There were 382 total infant deaths reviewed, representing 46.4% of all cases reviewed. Of the total number of infant deaths (854) in Pennsylvania in 2019, 44.7% were reviewed.

The second largest number of deaths by age group is children age 18 to 21 years. In Pennsylvania, the death rate of young adults age 18-21 years old (70.0 per 100,000 population) in 2019 was lower than the national rate (75.2 per 100,000 population). Youth age 18 years through 21 years of age accounted for 29.6% of child deaths reviewed. Of the total number of deaths of youth age 18 to 21 years (490) in Pennsylvania in 2019, 50.1% were reviewed.

Combined, these two age groups represent 76.0% of all child deaths reviewed in Pennsylvania.

An examination of reviewed cases by causes of death showed the following:

- Of the total 382 infant (less than 1 year of age) deaths reviewed, 162 (42.4%) were due to prematurity.
- An examination of Pennsylvania's reviewed infant deaths for 2019 revealed that 67 (7.8%) of the 854 infant deaths were SUID-related cases.
- Of the 97 reviews conducted on deaths occurring in children aged 1 through 9 years, the most frequent cause of death was cancer identified in 15 cases (15.5%).

- In the 101 reviews conducted on deaths occurring in children aged 10 through 17 years, the most frequent cause of death was assault, weapon, or person's body part over multiple manner of death categories to include homicides, suicides, and accidents, identified in 29 cases (28.7%). Assault, weapon, or person's body part includes causes of death involving firearms, sharp instruments, or when a person's body part has been used as a primary means of the assault or injury.
- The 244 reviews conducted on deaths of youth aged 18 through 21 years revealed the most frequently occurring cause of death was assault, weapon, or person's body part over multiple manner of death categories to include homicides, suicides, and accidents, identified in 75 cases (30.7%). In 2019, 116 of the reviewed deaths were categorized as assault, weapon, or person's body part. The majority of the deaths, 96 cases (82.8%) occurred among youth between 15 and 21 years of age. Intentional strangulation, either by suicide or homicide, is also included.
- There were 50 cases reviewed for 2019 in which suicide was the identified manner of death. In 30 of those cases (60.0%), assault, weapon or person's body part was the most frequent cause of death. Of the suicide deaths reviewed, 28 (56.0%), of the youth were age 18 years old or older.
- In 28 (51.9%) of the 54 cases involving poisoning, overdose, or acute intoxication, the manner of death was determined to be accidental. Of the poisoning deaths, 44 (81.5%) of the children were 18 years old or older.
- Of the total deaths in children reviewed for 2018, 60 cases (7.3%) involved a motor vehicle or other means of transportation. Based on the 60 motor vehicle deaths reviewed, 51 (85.0%) involved youth age 15 years to 21 years.

Preventability

Based on the review data contained within the NCFRP-CRS for deaths occurring in 2019, 127 deaths (15.4%) were determined to have been preventable by the local CDR teams. Of these preventable deaths reviewed, the manner of death was accidental in 86 (67.7%) deaths. Deaths of youth age 18-21 years account for 90 (70.9%) of the preventable deaths. It is important to note the determination of preventability is a subjective measure determined by local teams based on the information available at the time of the review.

Program Recommendations

Data quality

While data quality remains a priority, many teams are reorganizing after review meetings were delayed due to COVID-19 mitigation efforts, team members assuming new COVID-19 related duties, and core member retirements.

As teams reorganize, they are encouraged to examine membership to ensure sufficient information is available to effectively review deaths. In addition, teams should consider how to share data and findings with local prevention partners.

CDR program data quality will continue to be addressed on an ongoing basis. With complete data entered in a timely fashion state and local CDR teams could:

- Focus on prevention strategies to address specific local needs;
- Provide data supported recommendations to county executive staff;
- Offer support for policy/ordinance changes;
- Effect improved coordination/collaboration with local entities; and
- Enhance the state team's advocacy efforts for state level recommendations.

Data found in the NCFRP-CRS is the only data of its kind; there is nothing currently available that can provide this level of detail regarding the circumstances of a child's death. In addition to being valuable in identifying effective and appropriate prevention efforts, data obtained through death reviews is

essential to monitoring and evaluating those efforts. To be effective, the quality and timeliness of this data needs to be addressed and core variable fields with missing/unknown entries need to be drastically reduced or eliminated. The department will provide teams with reports on their data quality so that teams can target their efforts. In addition, starting with the first quarter of 2021 data, the department will import data from BHSR's birth and death files directly in to the NCFRP-CRS to assist local teams with data entry.

Disparities and Equity

CDR provides a unique opportunity to examine all circumstances surrounding a child's death, including the social context. The data clearly shows Black or African American children die at higher rates than white children. It behooves CDR to ask questions during reviews about why these disparities exist and what social, environmental, and societal factors are influencing the disparities, as well as to document their findings. The answers to these questions can help frame prevention recommendations and efforts that will help to address the social determinants of health and promote health equity. The department continues to provide training opportunities and technical assistance that focus on eliminating disparities, achieving equity and improving outcomes for all of Pennsylvania's children and youth.

Preventability

Preventability is a subjective determination made by local CDR teams based on the information available about the child's death at the time of review and the perspectives of local CDR team members. The BFH plans to assist teams in adopting a public health approach to determining whether deaths are preventable. Through webinars and written materials teams will be encouraged to identify social, environmental, and political determinants of health influencing death and to make recommendations for prevention strategies that address these underlying factors as a means to potentially reduce deaths from a variety of causes.

Local CDR team recommendations

The current application for the Title V Maternal Child Health Services Block Grant funding includes strategies for implementation of CDR prevention recommendations to inform the programs, policies and practices throughout the BFH. Local CDR team recommendations that have statewide impact will be assessed for viability and shared within the BFH and other appropriate entities. A format for sharing the recommendations is being developed and piloted. Internal teams have begun to meet to bridge efforts and to examine CDR recommendations.

Methods

An effective review requires using the information about the set of circumstances leading up to and causing a child death to improve systems and prevent future child deaths. The process is initiated when information collected from death certificates, birth certificates, and traffic accident reports is compiled by department staff and securely transferred to local CDR teams on a quarterly basis. Local teams use this information to initiate collaborative, multidisciplinary reviews. The death review process includes gathering available information regarding the circumstances related to the child's death and is not limited to only those items contained within death certificates. This includes, among other data, information derived from law enforcement reports, coroner reports, children and youth services records, emergency medical services trip sheets, hospital records and traffic accident reports. Cases are specifically assessed for preventability.

Currently, 62 teams represent all 67 Pennsylvania counties. Data regarding CDR reviews for this report are gathered through the NCFRP-CRS based on information provided by counties. Only data included in the system can be reviewed and analyzed. The following information is known regarding how many counties were actively reviewing cases and entering data in the NCFRP-CRS prior to COVID-19 mitigation efforts:

- Thirty-six counties were meeting regularly and entering case data.
- Seven counties were meeting but were not entering data.
- Sixteen counties were not known to be meeting and were not entering data.
- Two counties had no deaths in 2019.

Local teams are comprised of community leaders who represent organizations and agencies that serve and protect children within their respective counties. Local teams' core membership includes representation from the (1) coroner's or medical examiner's office, (2) district attorney's office, (3) local law enforcement, (4) court of common pleas, (5) medical and emergency medical communities, (6) county children and youth agency, and (7) public health agency. Most teams also include representation from behavioral health services, substance misuse treatment, education and prevention partners.

Local CDR teams enter the data collected through the child death review process into the NCFRP-CRS. Department staff as well as the local CDR teams can then export and analyze the CDR data to better understand the manner and cause of death and all the factors present that may have led to each death reviewed. Department staff analyzed the 2019 data to determine the most common causes of death by age, gender, and race/ethnicity, using frequencies of death by cause and manner to determine which deaths were considered preventable and to identify factors that contributed to the deaths that can be used to inform prevention efforts both locally and statewide.

The CDR data are supplemented with data from the CDC WONDER. This is a free online database maintained by the CDC (wonder.cdc.gov). For the purposes of the annual report, CDC WONDER provides mortality rates by age, race/ethnicity and gender for the state that would not otherwise be available through the NCFRP-CRS for context and comparison. Additionally, the annual report compares Pennsylvania mortality rates to the national rates to determine if Pennsylvania rates are analogous. Pennsylvania and national mortality rates derived from CDC WONDER were plotted over time from 2015 to 2019 to determine if rates were increasing or decreasing. The mortality rates, in conjunction with the data from the NCFRP-CRS, are used to identify populations most at risk for child deaths and to inform development of targeted prevention efforts/strategies. Most deaths are reviewed six to nine months after they occur. In Pennsylvania, local CDR teams review all deaths of children who are Pennsylvania residents, from birth through age 21 years. This includes deaths due to any cause or manner. A comprehensive review of a child's death requires the sharing of information from multiple sources on the wide-ranging set of circumstances leading up to and causing a child's death. As teams meet to conduct reviews, available information is compiled for each case. Each team has a

designated individual or individuals who subsequently enters this information into the NCFRP-CRS. Review data downloaded from the NCFRP-CRS were used in the development of this report. The data from the NCFRP-CRS used in the creation of this report were current as of June 1, 2021.

Limitations

Given that reviews are triggered by the filing of death certificates, the information available on death certificates may affect the review process through any limitations associated with the accuracy and reliability of the information stated on death certificates. For example, when cause of death is pending, teams sometimes set aside the reviews of those cases temporarily or locate the information from a participating coroner before initiating the review process.

It is important to recognize the number of deaths reviewed will not equal the total number of statewide deaths that occurred. According to BHSR data, there were 1,907 deaths in children 21 years of age and younger in 2019. Based on the review data contained within the NCFRP-CRS, 824 (43.2%) deaths were reviewed. Teams review deaths of Pennsylvania residents age 21 years and younger after death investigations are completed and death certificates are filed with the BHSR. The total number of deaths identified with BHSR data includes children and youth who resided in Pennsylvania but did not die in Pennsylvania. Typically, cases involving the judicial system are not reviewed until that process is concluded to avoid jeopardizing the judicial process. Cases are sometimes delayed in the review process when team members representing law enforcement or the district attorney's office determine conducting a child death review could potentially impact an investigation or a prosecution. In other cases, core information surrounding the circumstances of the death is unavailable; therefore, a complete review is not possible. This occurs for several reasons, including those cases wherein released records are not provided by an agency, county, or state (if the death occurred out-of-state) or the information on the death certificate is inadequate to proceed. It is important to note CDR data were captured based on information available to the teams at the time of the review. As a result, the data would likely be more complete if all information was available.

The information captured by the review team is to be entered and stored in the NCFRP-CRS. Data downloaded from that system were used in developing this report, and it is important to note cases within the system are at varying levels of completeness. While some review cases were initiated, not all the fields of information, or components, were completed during the review or by the time of this report. Data entry into NCFRP-CRS was dependent upon local teams' ability to identify staff to complete this task. Discussion or findings during reviews that were not entered in NCFRP-CRS or other reports completed by local teams were not included in this report. For these reasons, it is important to recognize frequencies and percentages based on available review data should be applied cautiously in drawing inferences on total deaths statewide.

Due to COVID-19 mitigation efforts beginning in March 2020, many of Pennsylvania CDR teams were unable to meet. Teams may not have been able to complete reviews of 2019 deaths and enter the information into the NCFRP-CRS prior to the final data pull for the analysis and writing of this report.

Findings

Data collected from reviews of child deaths occurring in 2019 are the basis for this report. Act 87 of 2008 defines a child as an individual 21 years of age and under. Reviews are conducted of children's deaths from birth through age 21 years. Overall, there were slightly fewer deaths of children in 2019 than in 2018. The BHSR data shows that there were 1,907 deaths of children in 2019, reflecting a 0.83% decrease from 1,923 deaths in 2018. Of the 1,907 deaths occurring in 2019, 824 (43.2%) were reviewed and entered in the NCFRP-CRS by local CDR teams. Of the 2018 deaths, 1,063 (55.3%) were reviewed and entered in the NCFRP-CRS by local CDR teams. Figure 1: Number of Child Deaths Reviewed, shows the number of Pennsylvania child deaths reviewed by local CDR teams over the past eight years. Many teams were unable to complete a review of all children's deaths in 2019 due to COVID-19 mitigation efforts which impacted the ability of teams to meet and some key team members capability to devote time and resources to CDR.

Figure 1: Number of Child Deaths Reviewed

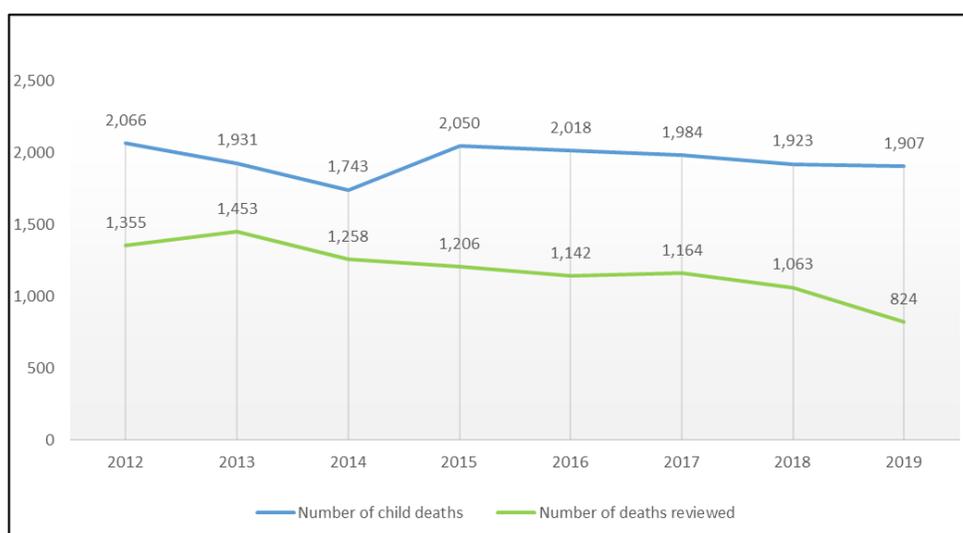


Figure 1: NCFRP-CRS, Year of Death 2019

Race

In 2019, 504 Black or African American children died in Pennsylvania. Of those deaths, 324 (64.3%) were reviewed by local CDR teams. In 2019, 1,101 white children died. Of those deaths, 411 (37.3%) were reviewed by local CDR teams.

Black or African American children die at a rate nearly twice that of white children.

It is important to note, while nearly two-thirds of child deaths involve white children, there is a larger population of white individuals in Pennsylvania. Rates are used when comparing populations because they standardize population size and provide a more meaningful comparison between population groups. Figure 2: Pennsylvania and National Death Rates per 100,000 Population by Race for All Children Age 21 and Under shows data from CDC WONDER and highlights rates of death for children in Pennsylvania and in the nation based on race.

Deaths of Black or African American children occur at a higher rate than those of other races. Both the national rate and the Pennsylvania rate of Black or African American children's deaths saw an increase from 2018 to 2019. In Pennsylvania, the rate increased from 88.5 per 100,000 population in 2018 to 91.75 per 100,000 population in 2019. Nationally, for the same time period, the rate

increased for Black or African-American children from 88.6 per 100,000 to 90.2 per 100,000. Black or African American children continue to die at a rate nearly twice that of white children.

Figure 2: Pennsylvania and National Death Rates per 100,000 Population by Race for All Children Age 21 and Under

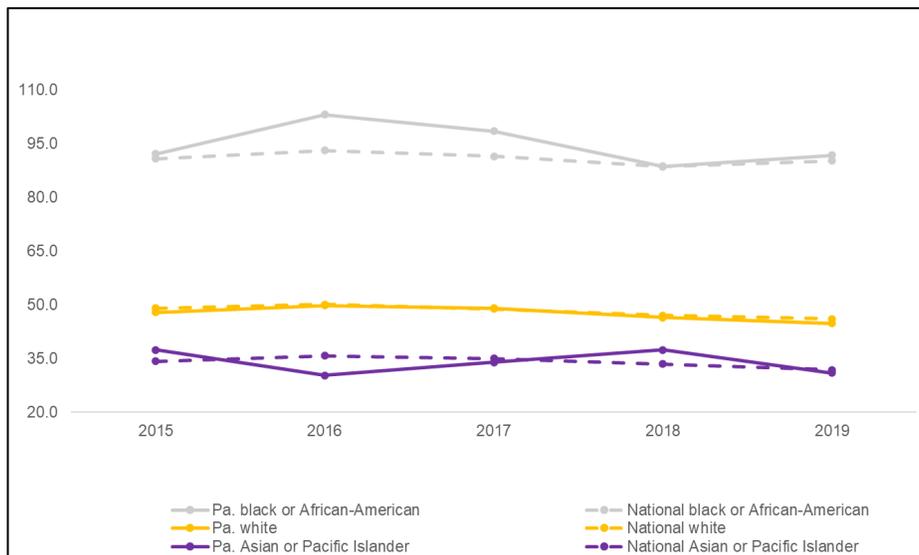


Figure 2: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2019 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2019, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html> on Jul 5, 2021 12:43:17 PM

While the national rate of death for white children remained relatively flat in 2019, the Pennsylvania rate saw a slight decrease. The Pennsylvania rate was 44.8 per 100,000 population in 2019 compared to 46.5 per 100,000 population in 2018. In 2019, the national rate was 46.1 per 100,000 population and in 2018, the rate was 47.0 per 100,000 population.

The rate of death for Asian or Pacific Islander children residing in Pennsylvania decreased from 37.4 per 100,000 population in 2018 to 31.0 per 100,000 population in 2019. The national rate decreased in 2018 from 33.5 per 100,000 population to 31.9 per 100,000 population in 2019.

An examination of the 824 reviewed child death cases by race and ethnicity revealed that: 1) 49.9% of the children were identified as white; 2) 39.3% of the children were identified as Black or African-American; 3) in 2.9% of the cases the children were identified as Asian 4) in 0.1% the children were identified as multi-racial; 5) in 0.1% the children were identified as Pacific Islander; 6) in 0.2% the children were identified as American Indian; and 7) in 7.2% the children's races were unknown or no response was recorded. See Figure 3: Reviewed Deaths by Race of Child. In 108 cases (13.1%), the children's ethnicity was identified as Hispanic/Latino (all races).

Figure 3: Reviewed Deaths by Race of Child

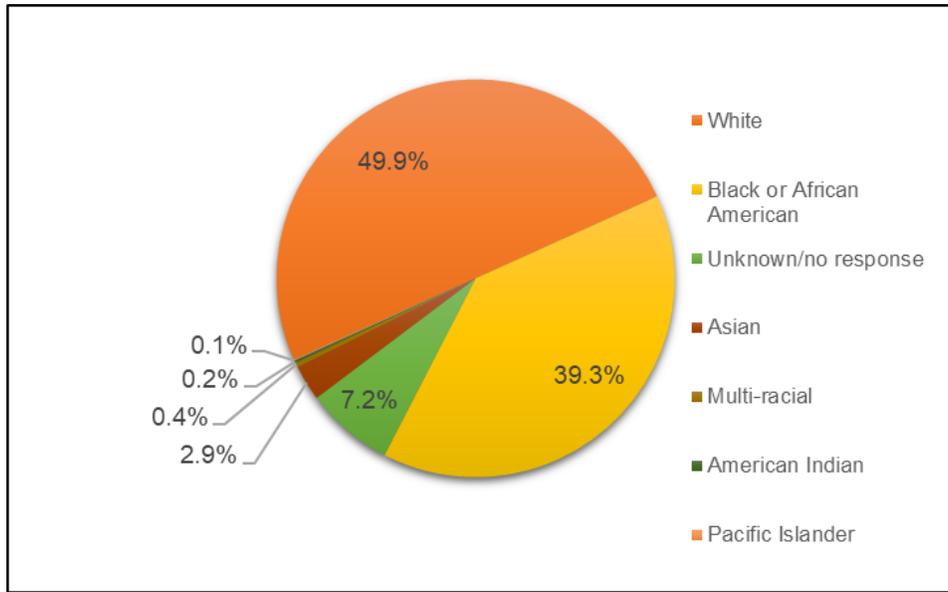


Figure 3: NCFRP-CRS, Year of Death 2019

Gender

Data from CDC WONDER reveals deaths of male children age 21 years and under in Pennsylvania occurred at a rate of 64.1 per 100,000 population in 2019, which is 1.6 times greater than the rate of females (39.1 per 100,000 population). The Pennsylvania rates for females and males is relatively equal to the national rates. The national and the Pennsylvania rates for females and males decreased slightly from 2018 to 2019. See Figure 4: Pennsylvania and National Death Rates per 100,000 Population by Gender for All Children Age 21 and Under.

Figure 4: Pennsylvania and National Death Rates per 100,000 Population by Gender for All Children Age 21 and Under

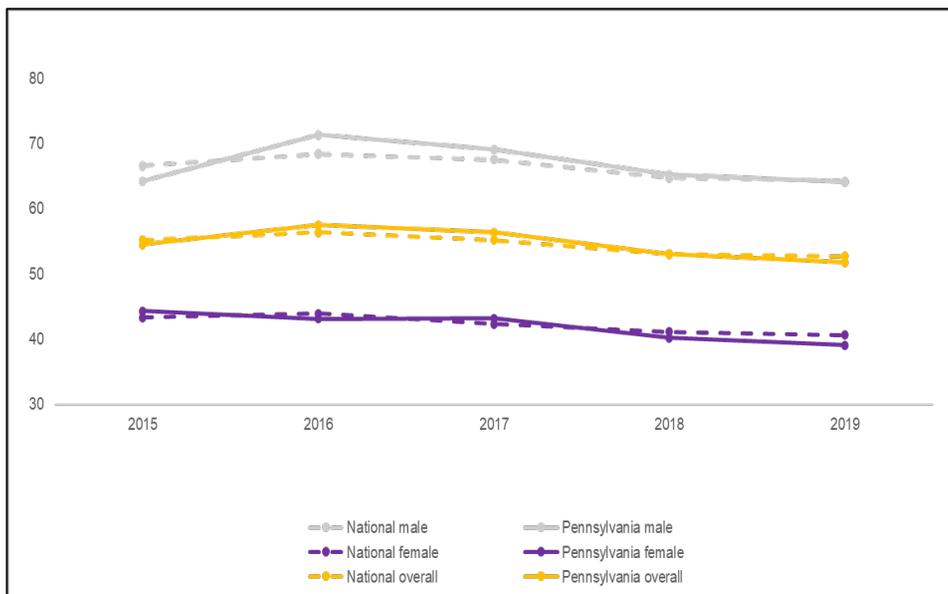


Figure 4: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2019 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2019, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html> on Jul 5, 2021 12:38:57 PM

In PA and nationally, the rate of death for male children and youth is 1.6 times greater than female children and youth.

Of the 824 children whose deaths were reviewed, 525 (63.7%) were male and 299 (36.3%) were female. More deaths of males were reviewed than females for every age category. See Figure 5: Reviewed Deaths by Gender and Age of Child. This is consistent with the rates of death being higher for males than females as shown in Figure 4: Pennsylvania and National Death Rates per 100,000 Population by Gender for All Children Age 21 and Under.

Figure 5: Reviewed Deaths by Gender and Age of Child

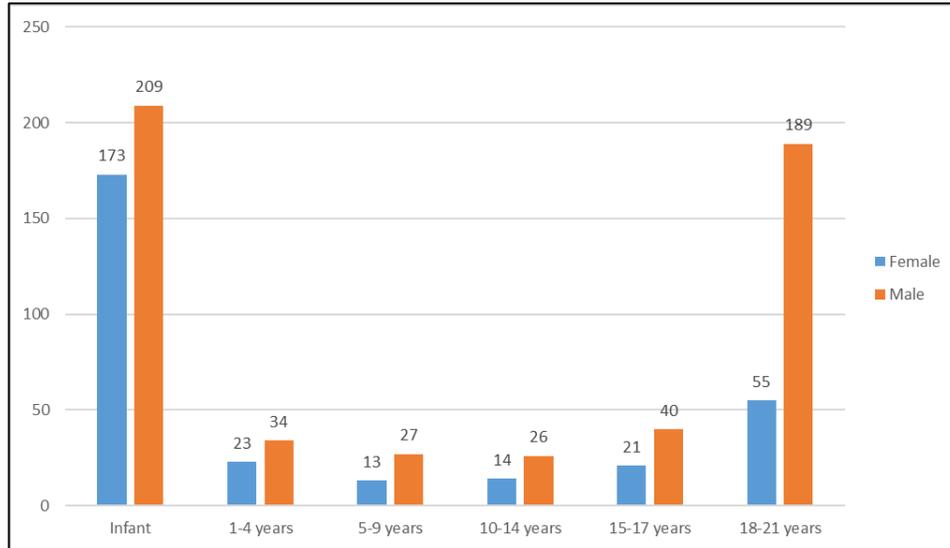


Figure 5: NCFRP-CRS, Year of Death 2019

Age

Data from CDC WONDER and BHSR shows that, both nationally and in Pennsylvania, the largest rate of deaths in 2019 by age group is infants (children less than 1 year old). The second largest rate of deaths by age group is children age 18 to 21 years. The Pennsylvania rate for infants (585.0 per 100,000 population) is higher than the national rate (553.0 per 100,000 population). The Pennsylvania rate for youth age 18-21 years (70.0 per 100,000 population) is lower than the national rate (75.2 per 100,000 population).

Based on CDC WONDER data for Pennsylvania, the death rate of infants decreased from 594.3 per 100,000 in 2018 to 585.0 per 100,000 in 2019. While the Pennsylvania rates are falling, the national rates are falling more quickly. Since 2015, the national rates have decreased 36.6 per 100,000 population and the Pennsylvania rate has decreased 29.7 per 100,000 population. See Figure 6: Pennsylvania and National Death Rates per 100,000 Population - Infants.

Figure 6: Pennsylvania and National Death Rates per 100,000 Population - Infants

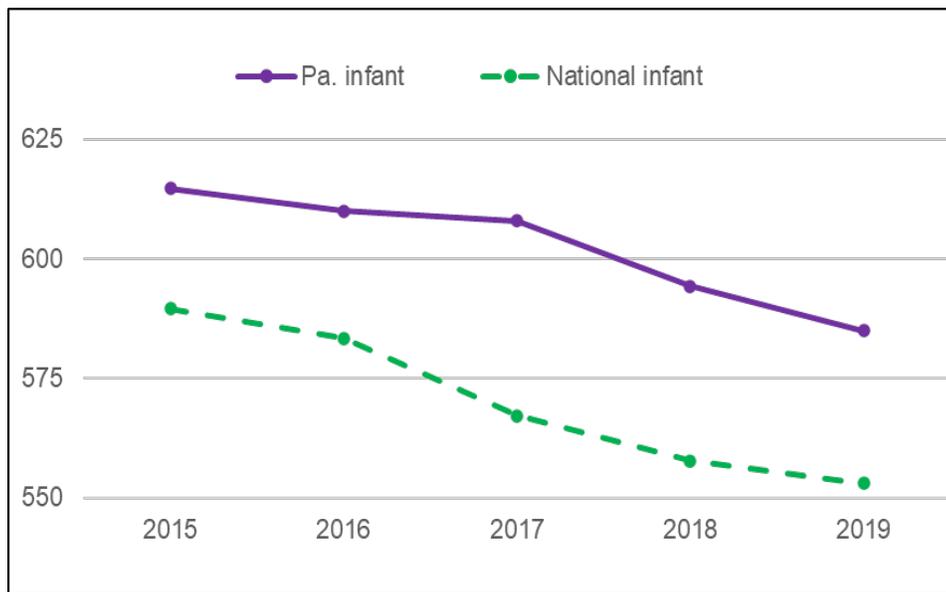


Figure 6: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2019 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2019, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html> on Jul 5, 2021 12:34:03 PM

Nearly half of the 2019 deaths reviewed were deaths among infants. There were 382 total infant deaths reviewed, representing 46.4% of all deaths reviewed. Of the total number of infant deaths (854) in Pennsylvania in 2019, 44.7% were reviewed. Children age 18 years through 21 years of age accounted for 29.6% of child deaths reviewed. Combined, these two age groups represent 76.0% of all child deaths reviewed in Pennsylvania. Of the total number of deaths of youth age 18 to 21 years (490) in Pennsylvania in 2019, 50.1% were reviewed.

In Pennsylvania, the death rate of young adults age 18-21 years old (70.0 per 100,000 population) in 2019 was lower than the national rate (75.2 per 100,000 population). The 2019 rate is considerably lower than the 2017 rate of 87.1 per 100,000 population. This is illustrated in Figure 7: Pennsylvania and National Death Rates per 100,000 Population by 18-21 Years of Age.

Figure 7: Pennsylvania and National Death Rates per 100,000 Population by 18-21 Years of Age

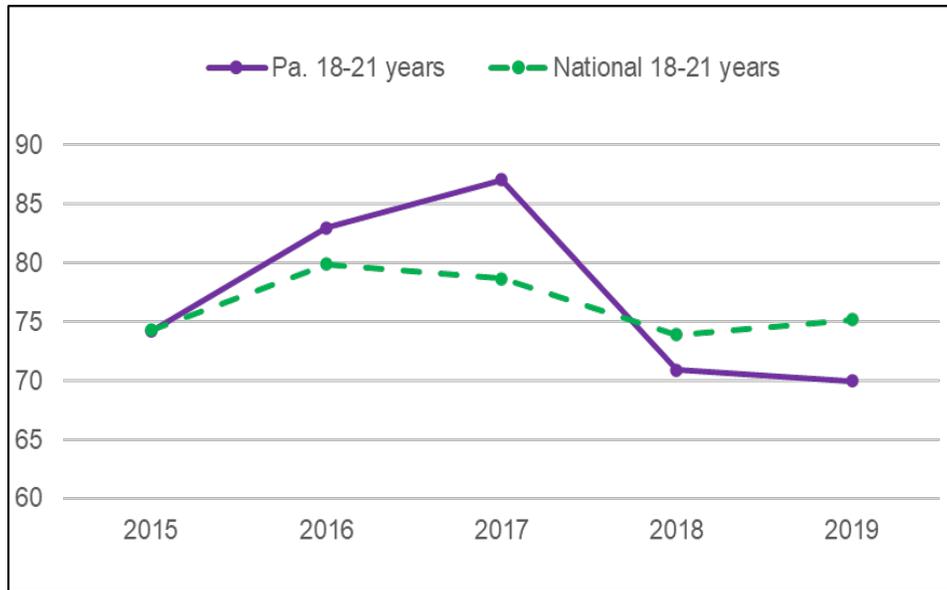


Figure 7: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2019 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2019, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html> on Jul 5, 2021 12:34:03 PM

Manner and Cause of Death

The manner and cause of death are determinations made by either the coroner or medical examiner. Pennsylvania has county government medical examiner offices in Philadelphia, Allegheny, and Delaware counties and elected coroners in the other 64 counties. Conclusions regarding manner and cause of death are made following either an autopsy or medical review of the death. The manner of death relates to the categorization of circumstances of the death. The five categories of manner of death are natural, homicide, suicide, accident, and undetermined. The cause of death is the physical condition that directly contributed to the person's death. The underlying cause of death is either the disease or injury that initiated the train of morbid events leading directly to death or the circumstances of the accident or violence that produced the fatal injury.¹ A cause of death on the death certificate represents a medicolegal opinion that might vary among individual medicolegal officers.

The task of the medical examiner or coroner is to determine the cause and manner of an individual's death. The medical examiner or coroner must use all information available to reach a determination about the death. This may include information from their investigation, police reports, staff investigations and discussions with the family and friends of the decedent. Determining the manner and cause of death can be straightforward, or it may take weeks or longer to determine.

It is important to note that within the NCFRP-CRS, manner of death is captured within seven possible categories. In addition to the five listed above, the system provides options for (1) pending and (2) unknown.

Child death review is a mechanism to describe the manners, causes, and circumstances of child deaths in more detail. Understanding these elements is important when developing effective strategies to prevent deaths. The information in Figure 8: Manner of Deaths in Reviewed Cases shows the percentage of reviewed deaths attributed to each of the seven categories of the manner of death for all age categories. For reviewed deaths of children from birth to age 14 years, the most frequent manner of death identified is natural (68.0%), whereas, for children ages 15 years and up, reviewed deaths are most often identified as accidental (37.0%).

Figure 8: Manner of Deaths in Reviewed Cases

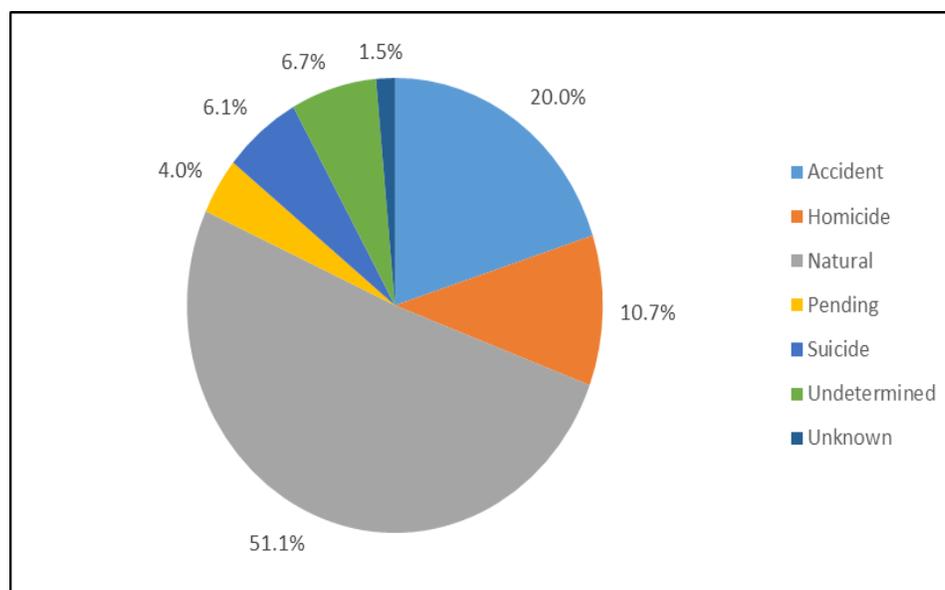


Figure 8: NCFRP-CRS, Year of Death 2019

Once the manner of death is determined, the cause or physical condition that directly contributed to the death needs to be concluded. The causes of death are broken down into three broad categories:

- Medical conditions — deaths directly attributed to some type of disease or illness as the cause of death. The manner of these deaths is typically defined as natural.
- External causes — deaths that were directly a result of some external action against the body. The manner of these deaths can be accident, homicide, or suicide.
- Unknown/undetermined — deaths for which a cause cannot be immediately identified.

Of the total 824 cases reviewed in 2019, the category of medical conditions represented the single highest frequency with 413 cases (50.1% of the total deaths reviewed). The most frequent cause of death for these cases was prematurity (39.5%).

The next highest category for causes of death reviewed was external causes, with 309 (37.5%) of the total deaths reviewed. The most frequent causes of death within external causes were assault, weapon, or person's body part (37.5%), motor vehicle accidents (19.4%) and poisoning (17.8%), which includes intentional and unintentional overdose deaths.

An examination of the causes of death by age group shows:

- An examination of the causes of death within the infant age group (less than 1 year old) revealed the majority of infant deaths were due to prematurity. Of the total 382 infant deaths reviewed, 162 (42.4%) were due to prematurity.
- Of the 97 reviews conducted on deaths occurring in children aged 1 through 9 years, the most frequent cause of death was cancer identified in 15 (15.5%).
- In the 101 reviews conducted on deaths occurring in children aged 10 through 17 years, the most frequent cause of death was due to assault, weapon, or person's body part, identified in 29 cases (28.7%).
- An examination of the 244 reviews conducted on deaths of youth aged 18 through 21 years revealed the most frequently occurring cause of death was assault, weapon, or person's body part, identified in 75 cases (30.7%).

Table 1: Reviewed Deaths by Causes of Death and Age Category shows 2019 child deaths as identified by CDR reviews by cause and age category.

Table 1: Reviewed Deaths by Causes of Death and Age Category

		Infant	1-4 years	5-9 years	10-14 years	15-17 years	18-21 years	Grand total
Medical condition	Cause of death							
	Asthma/respiratory	2	2	5	2	1	1	13
	Cancer	2	6	9	4	5	9	35
	Cardiovascular	4	2	3	1	2	12	24
	Congenital anomaly	42	2	0	1	1	6	52
	Diabetes	0	0	0	0	0	1	1
	Neurological / seizure disorder	2	3	2	3	1	7	18
	No response	1	2	0	1	0	1	5
	Other infection	8	1	3	2	3	3	20
	Other medical condition	14	6	2	4	3	9	38
	Other perinatal condition	18	0	0	1	0	0	19
	Pneumonia	9	2	0	0	0	2	13
	Prematurity	162	1	0	0	0	0	163
	SIDS	6	0	0	0	0	0	6
	Unknown	2	2	0	0	1	1	6
	Subtotal medical condition	272	29	24	19	17	52	413
External cause	Assault, weapon, or person's body part	5	4	3	8	21	75	116
	Asthma/respiratory	0	1	0	0	0	0	1
	Drowning	0	1	2	2	2	3	10
	Fall or crush	1	2	1	1	2	6	13
	Fire, burn, or electrocution	1	3	8	1	0	1	14
	Motor vehicle and other transport	1	4	1	3	8	43	60
	No response	1	0	0	0	1	0	2
	Other	3	0	0	5	2	7	17
	Poisoning, overdose or acute intoxication	1	2	0	0	7	45	55
	Undetermined	2	0	0	0	0	0	2
	Unintentional asphyxia	15	0	1	1	0	1	18
	Unknown	0	0	0	0	0	1	1
	Subtotal external cause	30	17	16	21	43	182	309
Unknown	Undetermined if injury or medical cause	44	3	0	0	1	7	55
	Unknown	36	8	0	0	0	3	47
	Subtotal unknown	80	11	0	0	1	10	102
	Grand Total	382	57	40	40	61	244	824
Table 1: NFR-CRS, Year of Death 2019								

Prematurity

A premature birth is one that occurs before the 37th week of gestation. CDC WONDER data shows in 2018 (most recent data available), the rate of death for Pennsylvanian children who were born to a Black or African-American person before 37 weeks gestation (65.4 per 1,000 live births) was 1.5 times the rate for children born to a white person (42.4 per 1,000 live births).

The rate of death of children born before the 37th week of gestation to a Black or African American person is 1.5 times the rate for children born to a white person.

Local CDR teams reviewed 163 deaths where the cause was listed as prematurity. Of the 163 deaths in which prematurity was the cause, 75 (46.0%) of the individuals giving birth had some level of prenatal care. Of the deaths reviewed, 13 (0.08%) of the individuals giving birth smoked at some time during the pregnancy and, in 100 cases (61.3%), the smoking status of the individuals giving birth was unknown or not reported. In all of the prematurity deaths reviewed, the infant's gestational age was reported. In 89 (54.6%) of the reviewed prematurity deaths, the infant was born extremely premature (less than 28 weeks).

Sudden Unexpected Infant Deaths (SUID)

According to the CDC, about 3,600 infants die suddenly and unexpectedly each year in the United States.² These deaths are called sudden unexpected infant deaths (SUID). An autopsy alone cannot always explain these deaths without investigating the scene and reviewing the infant's medical history. The most common causes of SUID include the following:

- Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant less than one year old that cannot be explained after a thorough investigation that includes a complete autopsy, examination of the death scene and a review of the medical history.
- Unknown cause is the sudden death of an infant less than one year old that cannot be explained. Often, a thorough investigation was not conducted, and cause of death could not be determined.
- Accidental suffocation and strangulation in bed (ASSB) includes suffocation by (1) soft bedding (for example, pillows covering an infant's nose and mouth), (2) overlays (for example, when a person rolls on top of or against an infant), (3) wedging or entrapment (for example, when an infant is wedged between two objects such as a mattress and wall, bed frame or furniture) and (4) strangulation (for example, when an infant's head and neck are caught between crib railings).



Safe Sleep

It is commonly recognized that babies placed on their stomach or sides to sleep are at greater risk for SIDS than babies who are placed on their backs to sleep. In 1992, the American Academy of Pediatrics (AAP) recommended placing babies on their backs to sleep. As a result of growing public awareness and successful intervention strategies, the rate of SIDS deaths has declined nationwide. Despite a reduction in the incidence of SIDS since 1992, the decline plateaued in recent years. Furthermore, according to the AAP, concurrently, other causes of SUID that occur during sleep (including suffocation, asphyxia, and entrapment) and ill-defined or unspecified causes of death have increased in incidence.³ Consequently, in 2011, the AAP expanded the recommendations from focusing only on SIDS to focusing on a safe sleep environment.

Safe Sleep ABC's
Alone -- Your baby should sleep by themselves, never with another person or with anything else in the crib.

Back -- Your baby should always sleep on their back. Every time.

Crib -- Your baby should sleep in a crib in your room. The crib should have a firm mattress and a tightly fitted sheet.

An examination of Pennsylvania's reviewed infant deaths for 2019 revealed that 67 (7.8%) of the 854 infant deaths were SUID-related cases. The causes of death for the SUID-related cases include pending, unknown/undetermined, unintentional asphyxia, and SIDS. CDC WONDER data for Pennsylvania shows that Black or African American infants die of SUID at more than twice the rate of white infants. This is illustrated in Figure 9: Pennsylvania and National Death Rates per 100,000 Live Births by Race for SUID Related Deaths. The Pennsylvania SUID-related rates of death for white infants is about the same as the national rate and the Pennsylvania rate for Black or African American infants is slightly lower than the national rate. Note: 2018 is the most recent data available for linked birth files in CDC WONDER.

Figure 9: Pennsylvania and National Death Rates per 100,000 Live Births by Race for SUID Related Deaths

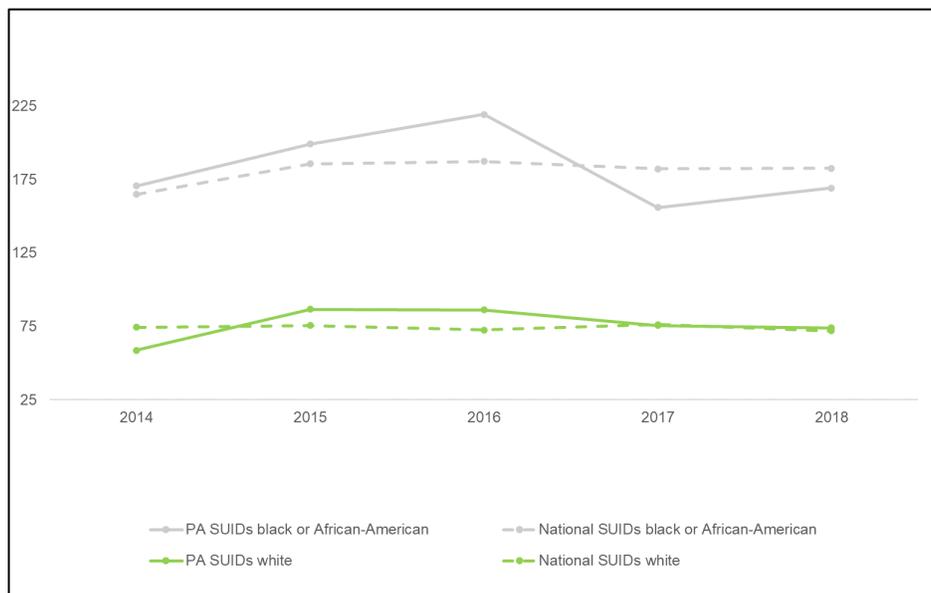


Figure 9: United States Department of Health and Human Services (US DHHS), Centers of Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics (DVS). Linked Birth / Infant Death Records 2017-2018, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program, on CDC WONDER On-line Database. Accessed at <http://wonder.cdc.gov/lbd-current-expanded.html> on Jul 10, 2021 12:49:30 PM

It is also important to note that Black or African American and white children were the only populations available for this comparison. Rates for American Indian, Alaskan Native, and Asian or Pacific Islander children are suppressed for Pennsylvania due to totals of less than 9 deaths. However, national rates for American Indian or Alaska Natives (186.4 per 100,000 live births) are significantly higher than for the white population (72.0 per 100,000 live births). Asian or Pacific Islander populations have the lowest rate (28.1 per 100,000 live births) of SUID-related deaths nationally.

The sleep locations for the 67 SUID-related deaths reviewed from the NCFRP-CRS varied. In 67.2% (45) of these cases, the child was placed to sleep in an unsafe sleep location. Of those cases, 57.8% (26) of the unsafe sleep locations was an adult bed. In 26.9% (18) of the SUID cases, the child was placed to sleep in the child's crib or bassinet. More than half (61.2%) of the cases identified as SUID-related deaths there was a safe sleep place available at the time of the incident.

Black or African American infants die of SUID at more than twice the rate of white infants.

Sudden Death in the Young

The Pennsylvania Department of Health, Bureau of Family Health (BFH) contracts with the Philadelphia Medical Examiner's Office (MEO) to conduct the Sudden Death in the Young (SDY) case registry. In 2019, the BFH funded the program with Title V funds. The MEO is responsible for identifying cases in Philadelphia, reviewing the deaths via its Child Death Review Team and Advanced Review Team, and entering the data learned from the reviews into the National Case Reporting System. The purpose of the review teams' meetings is to identify underlying causes and risk factors associated with the sudden and unexpected deaths in children birth to age 20 years and to use that information to address infant and child mortality through prevention efforts.

The families of the deceased are given an opportunity to consent to have the child's deoxyribonucleic acid (DNA) samples used for research or DNA banking which are stored at the SDY Biorepository. The opportunity for further research enhances prevention efforts at the local level and has the potential to reduce mortality rates for these deaths on a national level.

The MEO employs bereavement counselors who in addition to providing bereavement services to families also inform families of their option to participate in the research and banking of DNA through the SDY program. Of the 59 identified cases in the first year of the project, 23 families provided full or partial consent to have the sample stored and/or have the sample be part of the research project. The MEO has had more success in obtaining consents from families than all other jurisdictions in the nation participating in the SDY Case Registry due the work of the bereavement counselors. The counselors include the information regarding consent in their discussions with the families and provide the families with time to consider the option.

Figure 10: Causes of Death in Reviewed Sudden Death in the Young shows the causes of death for the identified and reviewed SDY cases. SUID deaths are a subset of SDY deaths. Of the SDY deaths, 28 (47.5%) involved infants and sleep-related events. Neurological issues were identified as the cause of the death in 7 (11.9%) of the SDY reviews. The neurological issues included congenital anomalies and epilepsy.

Figure 10: Causes of Death in Reviewed Sudden Death in the Young

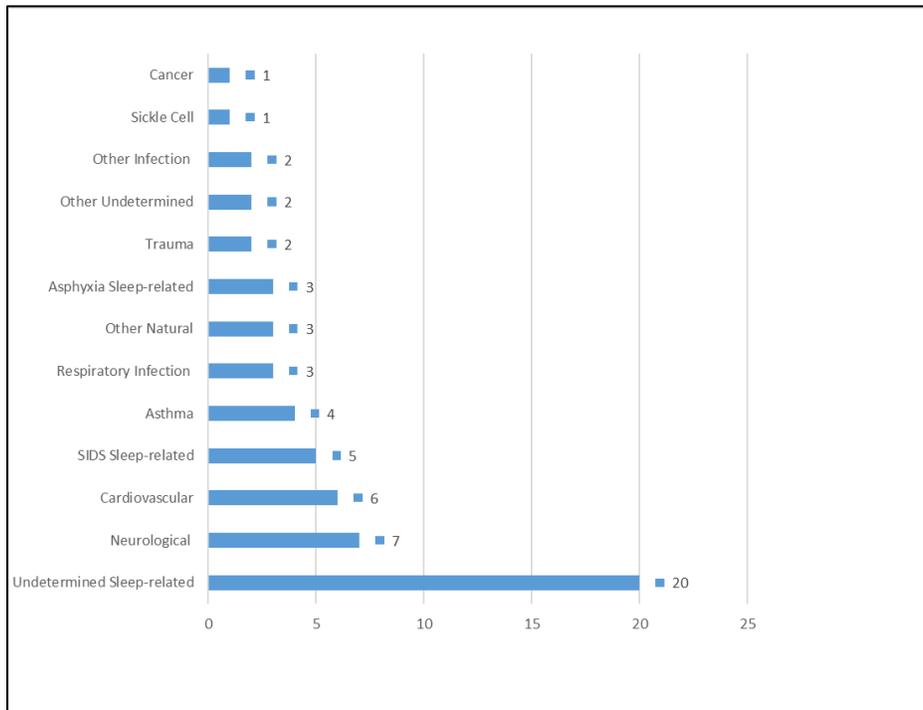


Figure 10: NCFRP-CRS, Year of Death 2019

Assault, Weapon, or Person's Body Part

During the child death review process, details pertaining to the circumstances surrounding the cases are discovered. The category of assault, weapon, or person's body part includes causes of death involving firearms, sharp instruments, or when a person's body part has been used as a primary means of the assault or injury. Intentional strangulation, either by suicide or homicide, is also included. This category accounts for the largest number of external injury deaths and crosses over multiple manner of death categories including homicides, suicides and accidents.

There were 116 cases reviewed for 2019 where cause of death was categorized as an assault, weapon, or person's body part. The majority of the deaths, 96 cases (82.8%) occurred among youth between 15 and 21 years of age. See Figure 11: Assault, Weapon or Person's Body Part by Age Category. Males accounted for 102 (87.9%) of reviewed deaths. Deaths involving assault, weapon, or person's body part among children and youth identified as Black or African American accounted for 72 (62.1%) reviewed deaths.

Figure 11: Assault, Weapon or Person's Body Part by Age Category

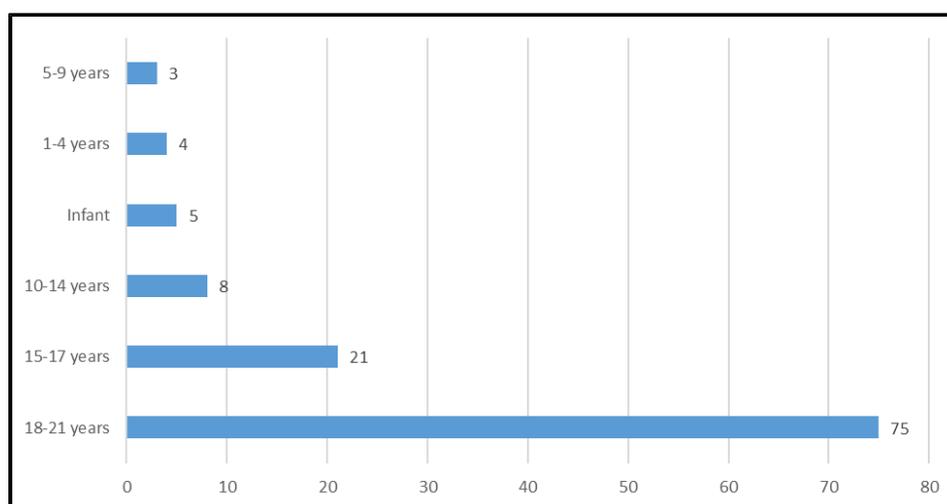


Figure 11: NCFRP-CRS, Year of Death 2019

An examination of the assault, weapon, or person's body part deaths reviewed by manner of death and type of weapon revealed that homicides accounted for most deaths, 84 deaths (72.4%). Of the firearms-related deaths (80), 67 (83.8%) were determined to be homicide, while 12 (15.0%) deaths were determined to be suicide. One cause of death (1.2%) was found to be undetermined.

Suicide Deaths

There were 50 cases reviewed for 2019 in which suicide was the identified manner of death. In 30 of those cases (60.0%), assault, weapon, or person's body part was the most frequent cause of death. In 18 (36.0%) deaths, the child shot themselves and in 20 (40.0%) deaths, the child hung themselves. A complete breakdown of these deaths is shown below in Figure 12: Reviewed Suicide Death by Cause.

Figure 12: Reviewed Suicide Death by Cause

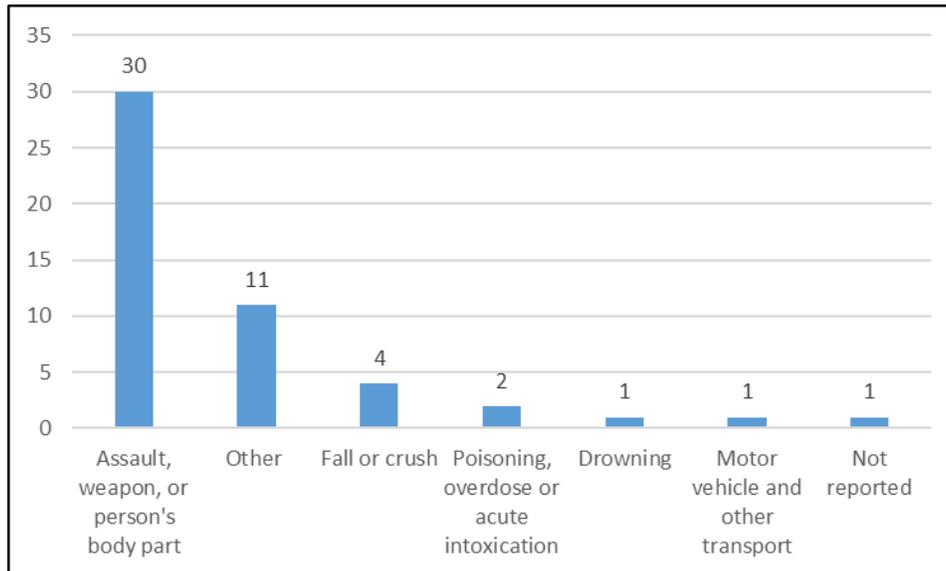


Figure 12: NCFRP-CRS, Year of Death 2019

White was the identified race of the child in 37 (74.0%) reviewed deaths. In 14 (28.0%) reviewed deaths, the child was age 11- 15 years and in 36 (72.0%) of the reviewed deaths the child was age 16-21 years. In 10 (20.0%) of the suicide cases reviewed, the child had communicated suicidal thoughts or ideations before dying by suicide. The data on suicide deaths have a significant portion of information listed as unknown or no response in the NCFRP-CRS.

Deaths Involving Poisoning, Overdose, or Acute Intoxication

An examination of the 2019 reviewed deaths revealed, in 54 cases, children’s deaths involved a reported poisoning, overdose, or acute intoxication. See the breakdown below in Figure 13: Reviewed Poisoning Deaths by Circumstance. In 28 (51.9%) of those cases, the manner of death was determined to be accidental. Of the poisoning deaths, 44 (81.5%) of the children were 18 years old or older. Of the total reviewed deaths involving poisoning, cases, 40 (74.1%) reviewed death involved males.

Figure 13: Reviewed Poisoning Deaths by Circumstance

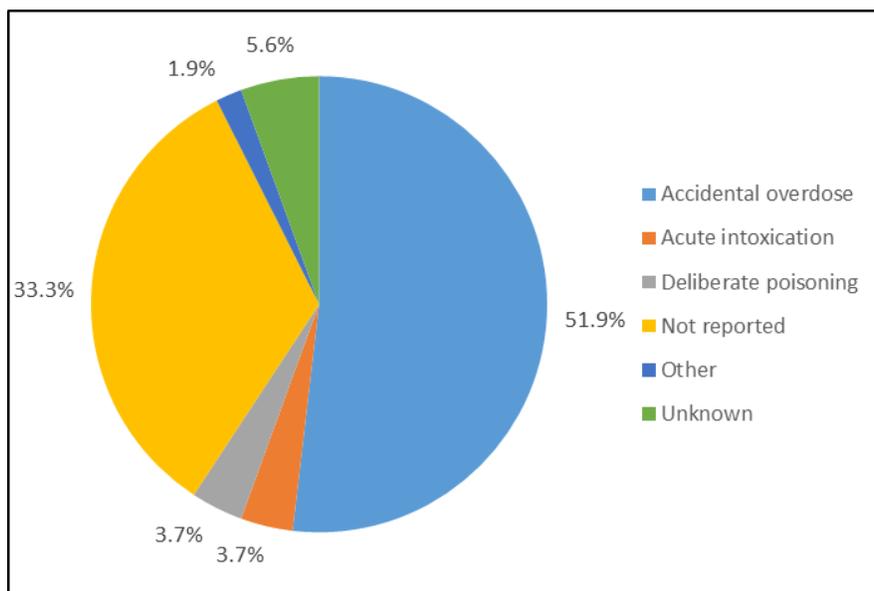


Figure 13: NCFRP-CRS, Year of Death 2019

Figure: 14 Types of Drugs Involved in Poisoning/Overdose Reviewed Deaths shows that 40 (74.1%) of the reviewed deaths involved illicit drugs. (Note: categories are not mutually exclusive. More than one type of substance could be involved in each case.)

Figure: 14 Types of Drugs Involved in Poisoning/Overdose Reviewed Deaths

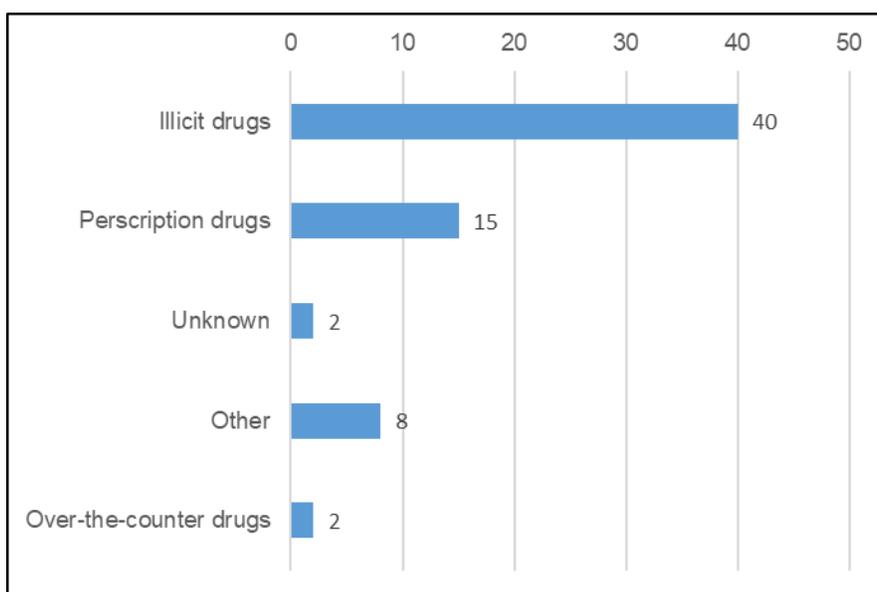


Figure 14: NCFRP-CRS, Year of Death 2019

Deaths Involving Motor Vehicles and Transportation

Of the total deaths in children reviewed for 2019, 60 cases (7.3%) involved a motor vehicle or other means of transportation. Based on the 60 motor vehicle deaths reviewed, 51 (85.0%) involved youth age 15 years to 21 years. This breakdown is further shown below in Figure 15: Reviewed Motor Vehicle Deaths by Age Category. Speeding was identified as a risk factor in 13 (21.7%) of the reviewed deaths. Drugs/alcohol was identified as a risk factor in 8 (13.3) of the reviewed deaths. Of the reviewed deaths, the child was a driver of the vehicle in 23 (38.3%) of the deaths. The child was a passenger in 10 (16.7%) of the reviewed deaths. The child was a pedestrian in 7 (11.7%) of the reviewed deaths. In the remaining 20 (33.3%) reviewed deaths the child's position was not reported by the local CDR team.

Figure 15: Reviewed Motor Vehicle Deaths by Age Category

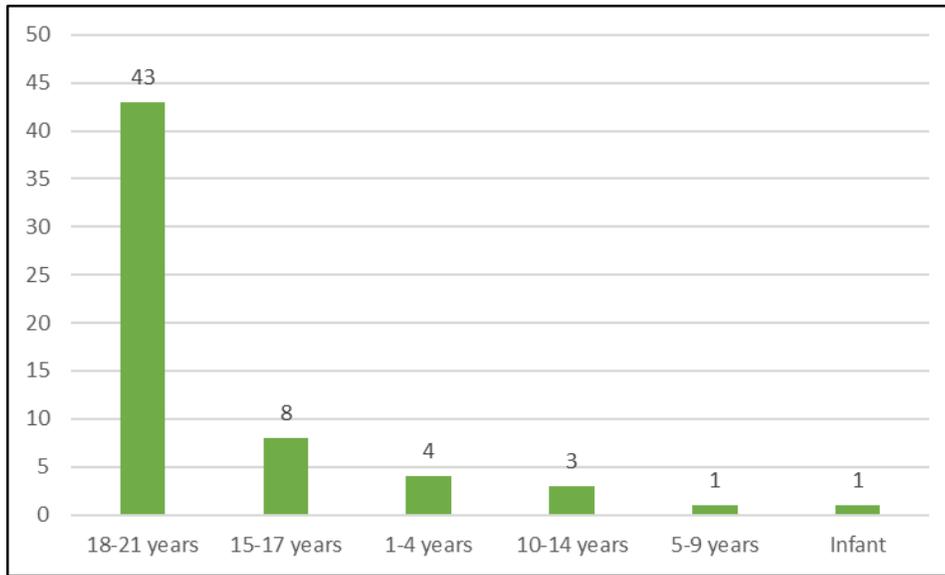


Figure 15: NCFRP-CRS, Year of Death 2019

Preventable Deaths

Based on the review data contained within the NCFRP-CRS for deaths occurring in 2019, 127 deaths (15.4%) were determined to have been preventable by the local CDR teams. Figure 16: Top 5 Causes of Death in Deaths Determined Preventable illustrates the top five causes of death that teams found to be preventable. Of the preventable deaths reviewed, the manner of death was accidental in 86 (67.7%) deaths. Deaths of youth age 18-21 years account for 90 (70.9%) of the preventable deaths. It is important to note the determination of preventability is a subjective measure determined by local teams based on the information available at the time of the review and the perspectives of local review team members. This analysis is based on the data available in the NCFRP-CRS at the time of this report.

Top 5 Causes of Death in Deaths Determined Preventable

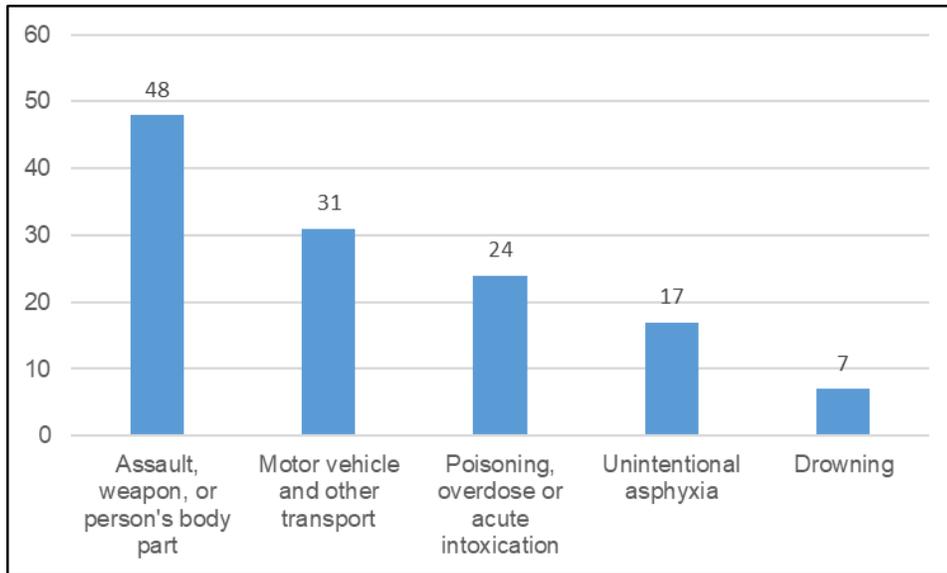


Figure 16: NCFRP-CRS, Year of Death 2019

Child Death Review Team Activities and Recommendations

The purpose of the reviews conducted by local CDR teams is to gather and examine data regarding the circumstances surrounding child deaths to promote safety and to reduce child fatalities through various activities. Activities are led by the CDR teams, CDR team members, or through collaborations with other local entities, including, but not limited to, coroners, local health departments, hospitals, law enforcement, home visitation programs, children's advocacy centers and schools. This section highlights some of the prevention efforts at the local and state level.

Local CDR Team Activity



The month of October is nationally recognized as Safe Sleep and SIDS Awareness Month. To recognize the importance of safe sleep, Family First Health, with cooperation from the York County CDR team, teamed with local artist Katie Trainer to paint a mural on the Family First Health windows at the front of the George Street center in York to share the safe sleep message. In addition, the Nurse Family Partnership nurses and staff at Family First Health provided information about safe sleep to patients and clients. The mural was coordinated with a social media messaging campaign and a YouTube informational video (<https://youtu.be/3cyPkqgRGSc>).



Local CDR Recommendations

Analysis showed that reviews of 101 cases (12.3%) of the 824 reviewed deaths resulted in recommendations. Not all recommendations are captured in the case reporting system as not all information is entered by local teams and some recommendations are made by examining aggregate data. The recommendations below may have been made by more than one local CDR team and are in various stages of implementation.

Safe sleep

- Provide ongoing education regarding safe sleep, including education targeting non primary caregivers.
- Educate families on sick babies and sleep: utilizing a de-humidifier and clearing nose.
- Educate families on hunger cues in formula fed babies, infant sleep patterns and diaper output.
- Educate families that goat milk is not recommended for babies less than one year of age.
- Educate families that breastfeeding exclusively and/or with supplementation for at least two months decreases the risk of SIDS.
- Institute Plans of Safe Care and follow-up for babies born with Fetal Alcohol Syndrome or Neonatal Abstinence Syndrome.
- Increase referrals to home visiting programs.
- Promote paid parental leave.
- Promote comprehensive health services for individuals giving birth (and babies born premature to individuals with health conditions).
- Support enhanced education regarding and treatment for substance misuse while pregnant.
- Continue to support the local Health Partnership by providing pack-n-play cribs and education on safe sleep.

Motor vehicle safety

- Continue to offer child seat safety inspections for proper installation and use of tether.
- Support community education on distracted driving dangers.
- Collaborate with Safe Kids and the local Center for Traffic Safety on young adult awareness education.
- Continue the Traffic Safety Education Project's community-based education work to promote safety of all roadway users.
- Continue to distribute safety materials about topics that affect children under the age of 21 years including child passenger safety, safe pedestrian and bicycle habits, the importance of wearing a seat belt, and the effects of impairment on driving.

Overdose prevention

- Provide universal access to naloxone and overdose prevention education.
- Encourage family and guardians to keep naloxone at their house if they know or suspect that anyone in the household is misusing substances.
- Encourage all emergency medical services (EMS) agencies to leave behind naloxone. When EMS responds to an overdose, the individual who experienced overdose, family and friends should receive naloxone to prevent future overdoses.
- Improve follow-up after release from the hospital, rehabilitation, halfway houses, and other treatment sites as well as when EMS responds to an overdose. Follow-up in the days and weeks following release and make sure patients are linked to continued care.
- Improve access to and utilization of Medication for Opioid Use Disorder (MOUD), specifically encouraging the use of evidence-based treatments such as Opioid Agonist Therapy (OAT).
- Provide education about the increasing prevalence of fentanyl in cocaine and other substances. Overdose is a risk for people who only use cocaine, due to the general presence of fentanyl with other substances, without the person's knowledge.
- Promote harm-reduction messaging such as avoiding using alone and using fentanyl test strips.
- Promote and increase prescription drug disposal sites. Prescribers should encourage their patients to dispose of excess prescription drugs, especially opioids, after use.
- Encourage messaging that reduces stigma related to substance use in families, schools and communities.
- Continue messaging about the dangers of heroin through local drug and alcohol agency.

Suicide prevention

- Identify and implement suicide prevention programs in schools, physical healthcare offices, community centers and human service facilities.
- Work with local intermediate units to disseminate information to all local school systems concerning suicide trends, suicide prevention programs and general behavioral health awareness.
- Ensure suicide prevention resources such as the National Suicide Prevention Hotline and Safe to Say are promoted on media outlets commonly used by today's youth. Some examples would be YouTube, Instagram, Twitter, TikTok, etc.
- Promote responsible firearm ownership and storage.
- Raise awareness of suicide trends with existing Student Assistance Program (SAP) providers, behavioral health treatment providers and child welfare workers.
- Ensure continuity of care and effective discharge planning for youth that are transitioning out of child serving systems (such as child welfare, juvenile probation and child and adolescent behavioral health) and entering adult systems.

- Raise awareness and assist law enforcement agencies, court system staff and human service providers in connecting “survivors of homicide” to behavioral health supports. Studies suggest that those who lost loved ones to homicide have a significantly elevated risk of both considering and attempting suicide.

Fire safety

- Support of Department of Human Services enhanced fire safety requirements for daycares.

Firearm safety

- Provide education to parents and the community on safe firearm storage to reduce children and youth access to guns.

Homicide prevention

- Promote the work of local anti-violence agencies.

Statewide CDR Activities:

SUID/SDY

Pennsylvania applied for and was accepted into the Centers for Disease Control and Prevention’s Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry. The SUID/SDY Case Registry builds upon the existing CDR program and the previous 3-year SUID grant work. The new SUID/SDY grant award expands Pennsylvania’s surveillance of SUID deaths to include the broader category of SDY deaths. SDY deaths include infants as well as children and young adults through 21 years old who die unexpectedly. Although little is known about the incidence of SDY, it is commonly associated with unexpected death, cardiac conditions such as cardiomyopathy or arrhythmias, and possible genetic forms of epilepsy. The SDY work began early in 2019. The 5-year grant funded program for both components runs from October 2018 to September 2023.

Safe sleep

The department first awarded the Trustees of the University of Pennsylvania a grant in 2016 to develop and implement an evidence-informed infant safe sleep education model. The focus of this approach is to move safe sleep education from discharge to arrival in the postpartum unit to allow for reinforcement of risk reduction methods for the duration of the hospital stay. The model safe sleep program for well newborns in the hospital setting development is complete and undergoes revisions as necessary. The program is now focused on expanding implementation to the entire state. As of 2020, the model safe sleep program was fully implemented in 14 of Pennsylvania’s 90 birthing hospitals (15%) and over 31,000 infants or 24% of Pennsylvania births in 2020 had caregivers who received safe sleep education through the program. The preliminary findings of the model safe sleep program include an 85% reduction in the incidence of unsafe items in infants’ hospital cribs. More information about the program can be found at www.pasafesleep.org.

State CDR team

The state CDR team began to meet in November 2018. The membership of the state CDR team mirrors that of effective local teams. While the CDR state team does not review cases, the vision of the group is to join with key government officials to work on policy and legislative recommendations regarding reduction of preventable child deaths and injury prevention strategies.

The state CDR Team implemented a new prevention recommendation framework. The framework process consists of three steps: assessment; development; and evaluation. Assessment includes review of data (CDR data and other relevant data), current prevention strategies occurring in Pennsylvania and other jurisdictions and best practices.

Using the information learned during the assessment phase, the state CDR Team brainstorms prevention strategies. The strategies are assessed for effectiveness and feasibility. Selected strategies are made actionable.

The result of this work will culminate in the development of a white paper for each type of death examined through the prevention framework. The white papers will serve as vehicles for sharing prevention strategies with partners that are positioned to take action. The team determines to which entities the white papers will be targeted. Ideally, targeted entities have the capability to implement/lead prevention strategies or already be involved in developing/implementing similar prevention strategies. The state CDR Team will develop a minimum of one white paper annually. The state CDR Team chose to begin its work with prevention framework by examining motor vehicle deaths. Recommendations resulting from the new prevention framework will be included in next year's annual report.

Program Recommendations

Data quality

While data quality remains a priority, many teams are reorganizing after review meetings were delayed due to COVID-19 mitigation efforts, team members assuming new COVID-19 related duties and core member retirements.

As teams reorganize, they are encouraged to examine membership to ensure that sufficient information is available to the team to effectively review deaths. In addition, teams should consider how to share data and findings with local prevention partners.

CDR program data quality will continue to be addressed on an ongoing basis. With complete data entered in a timely fashion state and local CDR teams could:

- Focus on prevention strategies to address specific local needs;
- Provide data supported recommendations to county executive staff;
- Offer support for policy/ordinance changes;
- Effect improved coordination/collaboration with local entities; and
- Enhance the state team's advocacy efforts for state level recommendations.

Data found in the NCFRP-CRS is the only data of its kind; there is nothing currently available that can provide this level of detail regarding the circumstances of a child's death. In addition to being valuable in identifying effective and appropriate prevention efforts, data obtained through death reviews are essential to monitoring and evaluating those efforts. To be effective, the quality and timeliness of this data needs to be addressed, and core variable fields with missing/unknown entries need to be drastically reduced or eliminated. The department will provide teams with data reports to help target their efforts. In addition, starting with the first quarter of 2021 data, the department will import data from BHSR's birth and death files directly in to the NCFRP-CRS to assist local teams with data entry.

Disparities and Equity

CDR provides a unique opportunity to examine all circumstances surrounding a child's death, including the social context. The data clearly shows Black or African American children die at higher rates than white children. It behooves CDR to ask questions during reviews about why these disparities exist and what social, environmental, and societal factors are influencing the disparities, as well as to document their findings. The answers to these questions can help frame prevention recommendations and efforts that will help to address the social determinants of health and promote health equity. The department continues to provide training opportunities and technical assistance that focus on eliminating disparities, achieving equity and improving outcomes for all of Pennsylvania's children and youth.

Preventability

Preventability is a subjective determination made by local CDR teams based on the information available about the child's death at the time of review and the perspectives of local CDR team members. The BFH plans to assist teams in adopting a public health approach to determining whether deaths are preventable. Through webinars and written materials teams will be encouraged to identify social, environmental, and political determinants of health influencing death and to make recommendations for prevention strategies that address these underlying factors as a means to potentially reduce deaths from a variety of causes.

Local CDR team recommendations

The current application for the Title V Maternal Child Health Services Block Grant funding includes strategies for implementation of CDR prevention recommendations to inform the programs, policies, and practices throughout the BFH. Local CDR team recommendations that have statewide impact will be assessed for viability and shared within the BFH and other appropriate entities. A format for sharing the recommendations is being developed and piloted. Internal teams have begun to meet to bridge efforts and to examine CDR recommendations.

Appendix A: Public Health Child Death Review Act (Act 87 of 2008)

PUBLIC HEALTH CHILD DEATH REVIEW ACT Act of Oct. 8, 2008, P.L. 1073, No. 87 AN ACT

Providing for child death review.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Public Health Child Death Review Act.

Section 2. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

"Child." An individual 21 years of age and under.

"Child death review data collection system." A data collection system approved by the National MCH Center for Child Death Review or a similar national organization.

"Department." The Department of Health of the Commonwealth.

"Local public health child death review team." A team representing a county or two or more counties comprised of professionals from organizations and local agencies who review cases of child deaths in accordance with protocols established by the State public health child death review team.

"Person in interest." A person authorized to permit the release of the medical records of a deceased child.

"Program." The Public Health Child Death Review Program established in section 3.

"State public health child death review team." A State multidisciplinary team comprised of local professionals and representatives of State agencies who review data submitted by local public health child death review teams, develop protocols for child death reviews and develop child death prevention strategies.

Section 3. Public Health Child Death Review Program.

(a) Establishment.--The department shall establish the Public Health Child Death Review Program which shall facilitate State and local multiagency, multidisciplinary teams to examine the circumstances surrounding deaths in this Commonwealth for the purpose of promoting safety and reducing child fatalities.

(b) Powers and duties.--The department, in cooperation with the State public health child death review team, shall have the following powers and duties in relation to the program:

(1) Assist in the establishment and coordination of local public health child death review teams.

(2) Coordinate the collection of child death data, including the development and distribution of a form to be used by local public health child death review teams to report information and procedures for sharing the data with State and local agencies as appropriate.

(3) Develop protocols to be used in the review of child deaths. These protocols shall not conflict with requirements set forth in 23 Pa.C.S. Ch. 63 (relating to child protective services), including, but not limited to, provisions relating to the review of child fatalities and near fatalities.

(4) Provide training and technical assistance to local public health child death review teams, local agencies and individuals relating to child deaths.

(5) Review reports from local public health child death review teams.

(6) Identify best prevention strategies and activities, including an assessment of the following:

- (i) Effectiveness.
- (ii) Ease of implementation.
- (iii) Cost.
- (iv) Sustainability.

(v) Potential community support.

(vi) Unintended consequences.

(7) Adopt programs, policies, recommendations, and strategies based on collected data to prevent child deaths.

(8) Review statutes and regulations relating to confidentiality and access to information relating to children from agencies responsible for the health and safety of children and propose recommended changes to appropriate Commonwealth agencies and the General Assembly.

(9) Provide public information and education regarding the incidence and causes of child injury and death and the reduction of risks to children to agencies, health care professionals, childcare professionals and the public.

(10) Submit an annual report to the Governor and the General Assembly by September of each year relating to the activities of the State child death review team, a summary of reports received from local child death review teams and recommendations relating to the reduction of risk of child injury or death.

Section 4. State public health child death review team.

(a) Composition.--A State public health child death review team shall be established by the department. The team shall consist of:

(1) The following individuals or their designees:

(i) The Secretary of Health, who shall serve as chairman.

(ii) The Secretary of Public Welfare.

(iii) The Director of the Office of Children, Youth and Families within the Department of Public Welfare.

(iv) The Commissioner of the Pennsylvania State Police.

(v) The Attorney General.

(vi) The Pennsylvania State Fire Commissioner.

(vii) The Director of the Bureau of Emergency Medical Services of the Department of Health.

(2) The following individuals who shall be appointed by the Secretary of Health:

(i) A physician who specializes in pediatric medicine.

(ii) A physician who specializes in family medicine.

(iii) A representative of local law enforcement.

(iv) A medical examiner.

(v) A district attorney.

(vi) A coroner.

(3) Representatives from local public health child death review teams.

(4) Any other individual deemed appropriate by the Secretary of Health.

(b) Powers and duties of the State public health child death review team.--The State public health child death review team shall:

(1) Review data submitted by local public health child death review teams.

(2) Develop protocols for child death reviews.

(3) Develop child death prevention strategies.

(4) Assist the department in implementing the program.

(c) Initial meeting.--The initial meeting of the State public health child death review team shall be held within 90 days of the effective date of this section.

(d) Additional meetings.--The department, in conjunction with the team, shall arrange for additional meetings to fulfill the duties of the team and goals of the program.

Compiler's Note: The Department of Public Welfare, referred to in this section, was redesignated as the Department of Human Services by Act 132 of 2014.

The Secretary of Public Welfare, referred to in this section, was redesignated as the Secretary of Human Services by Act 132 of 2014.

Section 5. Local public health child death review teams.

(a) Establishment.--Each county in this Commonwealth shall establish a local public health child death review team. Two or more counties may establish a local public health child death review team to operate on a regional basis to satisfy the requirements of this section.

- (b) Local public health child death review team.--Local teams shall be comprised of the following:
- (1) The director of the county children and youth agency or a designee.
 - (2) The district attorney or a designee.
 - (3) A representative of local law enforcement appointed by the county commissioners.
 - (4) A representative of the court of common pleas appointed by the president judge.
 - (5) A physician who specializes in pediatric or family medicine appointed by the county commissioners.
 - (6) The county coroner or medical examiner.
 - (7) A representative of emergency medical services selected jointly by the supervisors of all emergency medical organizations in the county.
 - (8) The director of a local public health agency or a designee.
 - (9) Any other person deemed appropriate by a majority of the local public health child death review team.

(c) Chairman.--The members of the local public health child death review team shall elect a chairman annually.

Section 6. Powers and duties of local public health child death review teams.

(a) Review.--A local public health child death review team shall review all deaths of children and may review the following information:

- (1) Coroner's reports or postmortem examination records.
- (2) Death certificates and birth certificates.
- (3) Law enforcement records and interviews with law enforcement officials as long as the release of such records will not jeopardize an ongoing criminal investigation or proceeding.
- (4) Medical records from hospitals and other health care providers.
- (5) Information and reports made available by the county children and youth agency in accordance with 23 Pa.C.S. Ch. 63 (relating to child protective services).
- (6) Information made available by firefighters or emergency services personnel.
- (7) Reports and records made available by the court to the extent permitted by law or court rule.
- (8) Reports to animal control.
- (9) EMS records.
- (10) Traffic fatality reports.
- (11) Any other records necessary to conduct the review.

(b) Data collection.--The local public health child death review team shall utilize the child death review data collection system to report its findings in accordance with protocols established by the State public health child death review team. The name and home address of the deceased child shall not be reported to the child death review data collection system.

(c) Reports.--A local public health child death review team shall submit annual reports on deaths reviewed to the State public health child death review team. The report shall include the following:

- (1) Identification of factors which cause a risk for injury and death, including modifiable risk factors.
- (2) Recommendations regarding the following:
 - (i) The improvement of health and safety policies in this Commonwealth.
 - (ii) The coordination of services and investigations by child welfare agencies, medical officials, law enforcement and other agencies.
- (3) Any other information required by the department.

(d) Recommendations.--A local public health child death review team shall make recommendations to local agencies relating to the procedures and other actions to reduce injury and death of children.

Section 7. Access to records.

(a) Juvenile records.--When deemed necessary for its review, a State or local public health child death review team may review and inspect all files and records of the court relating to a child pursuant to a proceeding under 42 Pa.C.S. Ch. 63 (relating to juvenile matters) in accordance with 42 Pa.C.S. § 6307 (relating to inspection of court files and records). However, this subsection shall not apply to files and records of the court subject to a child fatality or near fatality review pursuant to 23 Pa.C.S. Ch. 63 (relating to child protective services).

(b) Medical records.--Notwithstanding any other provision of law and consistent with the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191, 110 Stat. 1936), health care facilities and health care providers shall provide medical records of a child under review without the authorization of a person in interest to the State public health child death review team and to a local public health child death review team for purposes of review under this act.

(c) Other records.--Other records pertaining to the child under review for the purposes of this act shall be open to inspection as permitted by law.

Section 8. Confidentiality.

(a) Maintenance.--State and local public health child death review teams shall maintain the confidentiality of any identifying information obtained relating to the death of a child, including the name of the child, guardians, family members, caretakers or alleged or suspected perpetrators of abuse, neglect or a criminal act.

(b) Agreement.--Each member of the State and local public health child death review team and any person appearing before the team shall sign a confidentiality agreement applicable to all proceedings and reviews conducted by the State or local public health child death review team.

(c) Liability.--An individual or agency that in good faith provides information or records to a State or local public health child death review team shall not be subject to civil or criminal liability as a result of providing the information or record.

(d) Discovery.--The proceedings, deliberations and records of a State or local public health child death review team are privileged and confidential and shall not be subject to discovery, subpoena or introduction into evidence in any civil or criminal action.

(e) Meetings.--Meetings of the State or local public health child death review team at which a specific child death is discussed shall be closed to the public and shall not be subject to the provisions of 65 Pa.C.S. Ch. 7 (relating to open meetings).

(f) Attendance.--Nothing in this act shall prevent a State or local public health child death review team from allowing the attendance of a person, including a parent, with information relevant to a review, at a child death review meeting.

(g) Penalty.--A person who violates the provisions of this section commits a misdemeanor of the third degree.

Section 20. Regulations.

The department shall promulgate regulations as necessary to carry out the purposes of this act.

Section 21. Effective date.

This act shall take effect in 90 days.

Appendix B: Definitions

Act 87 of 2008: Pennsylvania's Public Health Child Death Review Act of Oct. 8, 2008 (see Appendix A).

Child: According to the Pennsylvania Public Health Child Death Review Act, a child is defined as an individual 21 years of age and under. Reviews are conducted on deaths occurring in this age group.

Child death rate: Number of child deaths per 100,000 population in a specified group.

Sudden Unexpected Infant Death (SUID): SUID is the death of an infant less than 1 year of age that occurs suddenly and unexpectedly, and for which the cause of death is not immediately obvious before investigation. Most SUIDs are reported as one of 3 types: Sudden Infant Death Syndrome (SIDS); unknown cause; or accidental suffocation and strangulation in bed.

SUID death rate: Number of SUID-related deaths per 100,000 live births.

Child death review (CDR): A multi-agency, multi-disciplinary process that routinely and systematically examines the circumstances surrounding child deaths in a given geographical area and a given age group.

Pennsylvania Child Death Review Program: The Pennsylvania CDR Program is designed to promote the safety and well-being of children and reduce preventable child fatalities through timely reviews of child deaths.

Pennsylvania State Child Death Review Team: The Pennsylvania CDR state team is comprised of representatives from agencies and organizations that focus on children in Pennsylvania. Aggregated information is shared with legislators and state policy makers to concentrate funding and program priorities on appropriate prevention strategies.

Pennsylvania's Child Death Review local teams: Local teams are comprised of community participants representing organizations and agencies that serve and protect children within their respective counties. CDR team members review child deaths and analyze data to develop prevention strategies.

End Notes

¹ Underlying Cause of Death: The underlying cause of death is either the disease or injury that initiated the train of morbid events leading directly to death or the circumstances of the accident or violence that produced the fatal injury. The underlying cause of death is the one to be adopted as the cause for tabulation or mortality statistics. Source: Handbook of Vital Statistics Systems and Methods, Volume 1: Legal Organizational and Technical Aspects, United Nations Studies in Methods, Glossary, Series F, No. 35, United Nations, New York 1991

² CDC - Sudden Infant Death Syndrome (SIDS). <https://www.cdc.gov/sids/AboutSUIDandSIDS.htm>. July 22, 2020. Content Source: National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health

³ American Academy of Pediatrics Announces New Safe Sleep Recommendations to Protect Against SIDS, Sleep-Related Infant Deaths. From American Academy of Pediatrics website: <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/american-academy-of-pediatrics-announces-new-safe-sleep-recommendations-to-protect-against-sids.aspx> . September 3, 2017