

Delaware CDRC

REVIEW & PREVENTION OF CHILD DEATHS



Child Death Review Commission

Annual Report for Calendar Year 2016



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Child Death Review Commission
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TO: The Honorable John Carney
Members of the General Assembly

FROM: Garrett H. C. Colmorgen, M.D.
Chairperson, Child Death Review Commission

DATE: July 18, 2017

SUBJECT: Calendar Year 2016 Child Death Review Commission Report

I am pleased to present you with the thirteenth Report of the Delaware Child Death Review Commission (CDRC). This report provides a summary of the work of the Panels and Commission during calendar year 2016.

Delaware appears to be making progress to decrease the mortality rate of its children. For example, Delaware's infant mortality rate declined by 19% between 2000-2004 and 2010-2014 due to the work of many of the professionals and community partners mentioned in this report. Although we have documented significant improvements, we must remember that the loss of any child is one death too many. Death reviews only identify the "tip of the iceberg." Every child who dies is representative of the much greater burden of morbidity carried by our community. The goal of the CDRC has been and will continue to be the prevention of future child deaths, and as a by-product, the reduction of child morbidity.

Maternal mortality trends in the US are of growing concern, and the work of the CDRC is helping to shed light on this important population health indicator in Delaware. This year's report includes a summary section covering all maternal deaths reviewed over the last six years in our state. The pregnancy-related mortality ratio in Delaware is on par with the national average which has been worsening over the past ten years: There is still much work to be done to prevent maternal deaths.

We hereby report prevention initiatives, collaborations with other Delaware agencies, increased data surveillance, and trainings for professionals and community members that reflect our mission. The Commission has identified the following key issues as priorities requiring attention:

- Social determinants of health
- Substance abuse and its detrimental impact on families and maternal child health outcomes
- Underutilization of evidenced-based home visiting programs

These issues were identified by the last annual report and need your continued support to prevent future child and maternal morbidity and mortality.

As Chair of the Child Death Review Commission, I want to thank you as Governor and the many members of the General Assembly who support the work of the Commission. Your commitment to reducing infant, child and maternal mortality in the State of Delaware will create better outcomes for Delaware's women and children.

Respectfully submitted,


Garrett H.C. Colmorgen, M.D.
Chair
Child Death Review Commission

Executive Summary

The Child Death Review Commission (CDRC) conducts three mortality review programs in Delaware for review of child deaths up to the age of 18 years, fetal and infant deaths occurring after 20 weeks gestation, and maternal deaths up to one year after the end of pregnancy. Efforts in 2016 focused on clearing the backlog of older cases with the goal of having mortality reviews occur within six months of death whenever possible. CDRC staff also worked to better implement national databases for each review program and standardize internal data tracking across the three programs.

Key Issues

Based on the review of Child Death Review (CDR), Fetal and Infant Mortality Review (FIMR) and Maternal Mortality Review (MMR) cases, three key issues emerged. These issues have been identified in previous years of review, and their continuing importance as prevalent risk factors in maternal and child deaths underscores their fundamental nature and the need for cross-sectorial coordination to address them. These key issues are: 1) social determinants of health, 2) substance abuse and addiction and 3) underutilization of evidence-based home visiting services. These issues are described in more detail below.

1. Social determinants of health

2016 marked the release of the Delaware ACEs (adverse childhood experiences) study. This milestone study quantifies, for a representative sample of the Delaware population, the prevalence of ACEs including: psychological, physical and sexual abuse, exposure to substance abuse, mental illness, domestic violence, criminal behavior in the household, parental separation or divorce, physical or emotional neglect, discrimination and bullying. Over half (55%) of the adult respondents had experienced at least one ACE, and 13% had experienced four or more ACEs, with more ACEs correlating with an increased prevalence of risky health behaviors or compromised health outcomes.¹ The data on the prevalence of exposure to ACEs complements data that the CDRC is gathering more routinely on the prevalence of ACEs in child deaths, maternal deaths and FIMR cases. While limited by the availability due to reliance on patient self-disclosure in some cases, CDRC panels have found that these psychosocial risk factors are a recurring theme. The Division of Family Services (DFS) history with the family was identified in 60% of CDR cases and 15% of FIMR cases. However in 60% of FIMR cases, DFS history was not known. Moving forward, full DFS histories will be obtained for all FIMR cases. Fifty-four percent of homicide victims had a history of maltreatment, and 80% of suicide victims had such a history as well. CDRC review panels have noted that both a child's history of exposure and the parents' history of exposure to ACEs are important and relevant.

2. Substance abuse and addiction

Substance abuse was a recurring risk factor for maternal, infant and child deaths. Two MMR cases involved mothers with a history of addiction. Among FIMR cases, use of illicit drugs was noted in 10% of

cases and was a contributing factor to the death in 4%. Among CDR cases, 19% of infants who died had intrauterine drug exposure history. This is a rate that is about 10-fold higher than the neonatal abstinence syndrome (NAS) rate among all live births of 18.5/1,000 live births.² Illicit drug exposure or impairment was noted in 26% of unsafe sleep deaths, 30% of suicide deaths and 15% of child homicides. The rising rates of opioid addiction and NAS, which increased 55% between 2010 and 2013, prompted the creation of the Joint Committee on Substance-Exposed Infants and Medically Fragile Children in 2015. The Committee applied for and was awarded a grant for In-Depth Technical Assistance for Substance-exposed Infants by the National Center on Substance Abuse and Child Welfare. The technical assistance began in September 2016. The goal is to strengthen a multidisciplinary effort to reverse the opioid epidemic and ameliorate its impact on women, children and families. The Committee has also worked with system partners to identify concerns that will need long term attention, such as the drafting of state legislation and the implementation of plans of safe care.

3. Underutilization of evidence-based home visiting services

Many evidence-based home visiting programs—such as Nurse Family Partnership and Healthy Families America—focus on the prenatal and infancy period. For that reason, the prevalence of referral to home visiting programs was only accessed for infant deaths reviewed by CDR and FIMR. Among CDR infant cases, only six out of 31 cases (19%) were referred to home visiting or community-based services. Of those families referred, half enrolled in the program. Among FIMR infant cases, only 7 out of 84 (8%) were referred to home visiting or community-based services, and two mothers enrolled. Based on review of 2016 findings from all three mortality review processes, the CDRC puts forth this supportive statement:

The Commission strongly supports improvement in the process for vulnerable populations to access and accept evidence-based home visiting services.

A plan is needed to streamline the referral process for the physician when there is a concern for a mother, no matter at what point in pregnancy or postpartum. There also needs to be more provider education about the feedback loop that has been established for home visiting staff to communicate with providers. For 2017, CDR and FIMR will track if mothers are seen in public clinics or private offices for prenatal care in order to determine if referral rates differ in these two patient populations.

Additional Findings

Child Death Review

Based on the review of a few cases with similar issues, the CDRC developed a subcommittee to explore the issue of action plans and procedures within schools to care for children with chronic health conditions. The first meeting of the Subcommittee for Chronic Health Conditions took place in December 2016. The goals for this subcommittee in 2017 are to research national legislative guidelines for health conditions in schools and evaluate the adequacy of Delaware's laws and regulations for enabling school staff to care for children.

Fetal and Infant Mortality Review

In 2016, 34% of FIMR cases overall had a maternal interview. In the postpartum period, a lack of documented family planning counseling was a FIMR finding in 43 out of the 84 cases reviewed (51%), and thus the most frequently noted finding. Four women (5%) accepted long acting reversible contraception (LARC) in the postpartum period.

Maternal Mortality Review: multiyear summary

2016 marked the sixth year of MMR in Delaware, over which time 24 cases of maternal deaths have been reviewed. With the aid of the Centers for Disease Control and Prevention (CDC), a multiyear summary report was compiled as there were now enough cases reviewed to report more quantitative findings. Fifty-eight percent of the MMR cases (14 out of 24) were pregnancy-related deaths, defined as the death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.³ Among the pregnancy-related deaths, the most commonly identified risk factors or critical factors were at the patient-level: factors such as a patient's lack of knowledge regarding a health condition, lack of patient compliance, and the presence of chronic disease. From the multiyear data review, it was also found that relying solely on the pregnancy checkbox on the death certificate for maternal death identification is problematic. The CDRC is collaborating with the Division of Public Health's (DPH) Office of Vital Statistics to explore linking birth and death certificate data to identify more accurately maternal deaths from 2017 onwards.



Table of Contents

Annual Report for Calendar Year 2016	1
Executive Summary.....	4
Key Issues.....	4
Additional Findings.....	5
Glossary of Terms.....	8
Introduction	9
Child Death Reviews	14
Overview	14
Infant cases: CDR and SDY Findings	16
Sleep-Related Deaths.....	20
Motor Vehicle Deaths	23
Fire Deaths	24
Drowning Deaths	24
Poisonings and Overdoses	24
Weapons-related Deaths	24
Suicide Deaths.....	26
Social Determinants of Health: Pertinent CDR and SDY Findings.....	27
Substance Abuse: Pertinent CDR and SDY Findings.....	30
Home Visiting: Pertinent CDR and SDY Findings.....	30
Child Death Review Recommendations.....	30
Fetal and Infant Mortality Review	32
Overview	32
FIMR Findings.....	36
Social Determinants of Health: Pertinent FIMR Findings	39
Substance Abuse: Pertinent FIMR Findings	41
Home Visiting: Pertinent FIMR Findings	42
Maternal Mortality Review	45
Overview: 2016	45
MMR Findings: 2016 Cases	45
Multiyear Summary: MMR 2011-2016	46

MMR Findings in Pregnancy-related Cases: Multiyear Review 2011-2016	47
Conclusion.....	49
Commissioners.....	50
CDR Panel Members	50
SDY Panel Members.....	50
SDY Secondary Medical Panel Members	50
FIMR New Castle County CRT Members.....	51
FIMR Kent/Sussex County CRT Members	51
MMR Panel Members	51
CDRC Location and Staff	51
References	53

Glossary of Terms

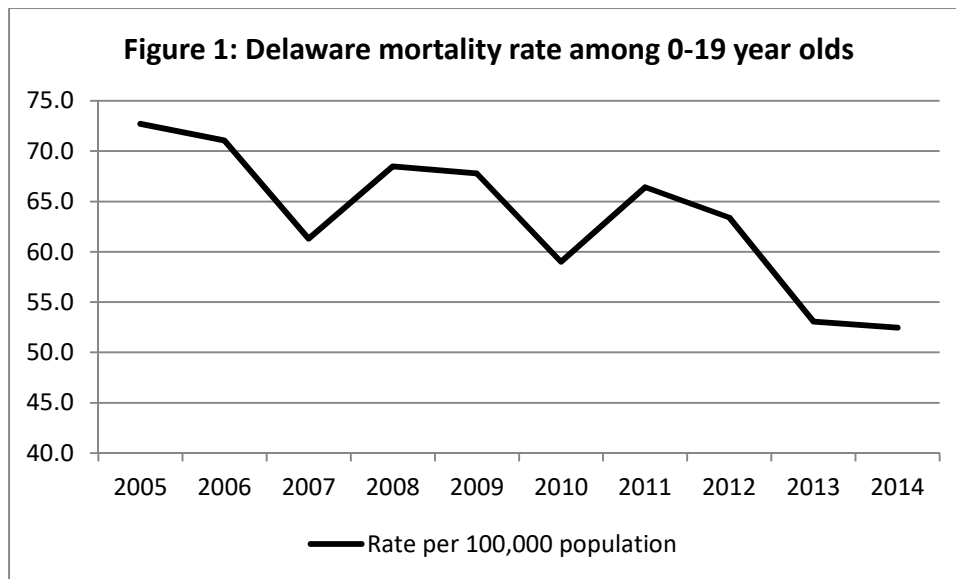
AAP – American Academy of Pediatrics	IMR – Infant mortality rate
ABC – All Babies Cry	IPV – Intimate partner violence
ACEs – Adverse childhood experiences	LARC – Long acting reversible contraception
ACOG – American Congress of Obstetricians and Gynecologists	MMR – Maternal Mortality Review
AHT – Abusive head trauma	MMRDS – Maternal Mortality Review Data System
AMCHP – Association of Maternal Child Health Programs	MMRIA – Maternal Mortality Review Information Application
CAN panel – Child Abuse and Neglect panel	MPHI – Michigan Public Health Institute
CAPTA – Child Abuse Prevention and Treatment Act	NAS – Neonatal abstinence syndrome
CDC – Centers for Disease Control and Prevention	NCFRP – National Center for Fatality Review and Prevention
CDR – Child Death Review	NFIMR – National Fetal and Infant Mortality Review
CDRC – Child Death Review Commission	PRAMS – Pregnancy Risk Assessment Monitoring System
CPAC – Child Protect Accountability Commission	Pregnancy-associated death – the death of a woman during pregnancy or within one year of the end of pregnancy, irrespective of cause
CRT – Case review team	Pregnancy-related death – the death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy
DAPI – Delaware Adolescent Program, Inc.	PPROM – Premature prolonged rupture of membranes
DFS – Division of Family Services	
DHHS – Delaware Household Health Survey	
DHMIC – Delaware Healthy Mother and Infant Consortium	
DPH – Division of Public Health	
DOSE – Direct On Scene Education	
FIMR – Fetal and Infant Mortality Review	
FOB – Father of the baby	
Hx – History	

PROM – Prolonged rupture of membranes
SBS – Shaken baby syndrome
SDY – Sudden Death in the Young
SIDS – Sudden infant death syndrome
SUDI – Sudden unexplained death in infancy
SUID – Sudden unexplained infant death

TAB – Therapeutic abortion
TISSPCAT – The Infant Safe Sleeping Program
Community Action Team
WIC - Special Supplemental Nutrition Program for
Women, Infants and Children

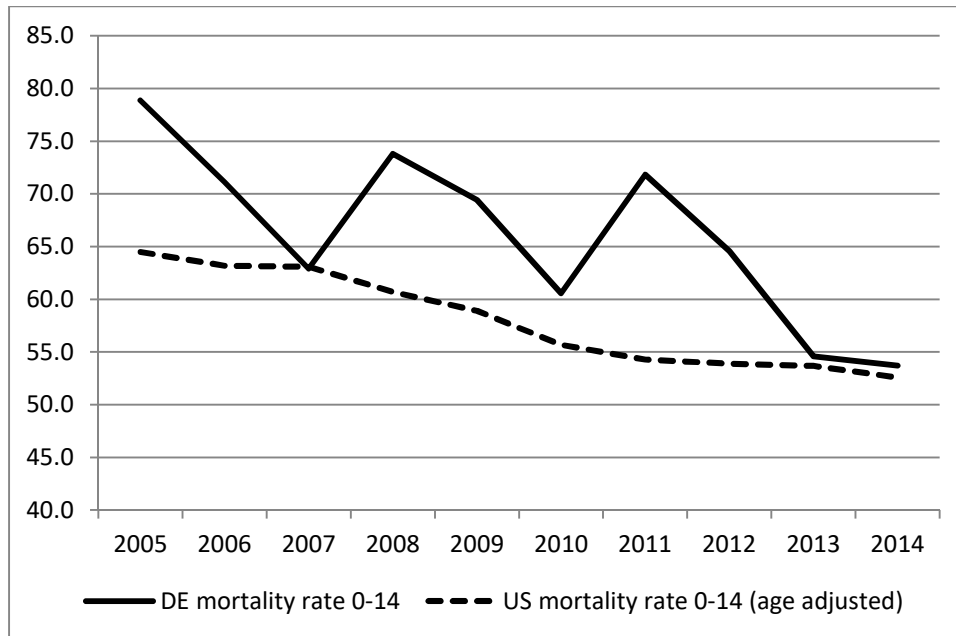
Introduction

Twenty-two years since its inception in 1995, the CDRC’s mandate to safeguard the health of Delaware’s children and mothers is still relevant. The Commission oversees three programs, child death review (CDR), fetal and infant mortality review (FIMR) and maternal mortality review (MMR). The findings from these reviews reflect ongoing changes in epidemiological trends and challenges affecting the optimization of maternal child health outcomes. While Delaware’s child mortality rate has decreased overall in the last decade for which rates are reported (2005-2014, Figure 1), with rates approaching the national average for 0-14 year olds (Figure 2), there is more inquiry into the impact of multigenerational exposure to adverse childhood experiences (ACEs) and substance abuse that continue to warrant close surveillance and multidisciplinary review.



Source: Delaware Health Statistics Center, Division of Public Health. Vital Statistics Reports. Downloaded from: <http://dhss.delaware.gov/dph/hp/annrepvs.html> on June 19, 2017.

Figure 2: Delaware and US rates of mortality among 0-14 year olds (per 100,000 children)

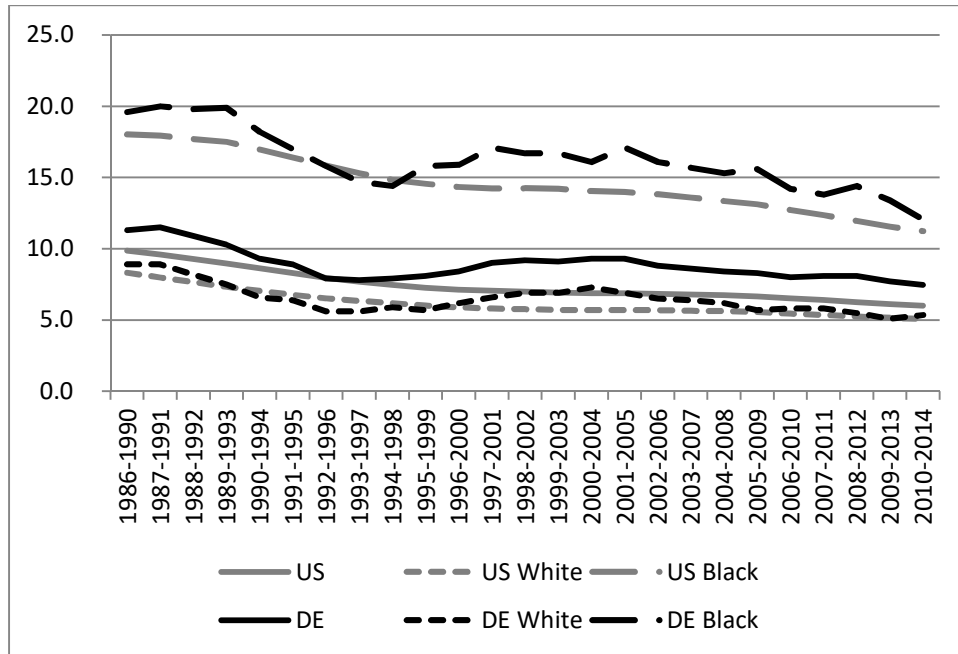


Source: Delaware Health Statistics Center, Division of Public Health. Vital Statistics Reports. Downloaded from: <http://dhss.delaware.gov/dph/hp/annrepvs.html> on June 19, 2017.

Centers for Disease Control and Prevention (CDC). CDC Wonder. Underlying cause of death, 1999-2015, 0-14 years. Downloaded from: <https://wonder.cdc.gov/controller/datarequest/D76> on June 19, 2017.

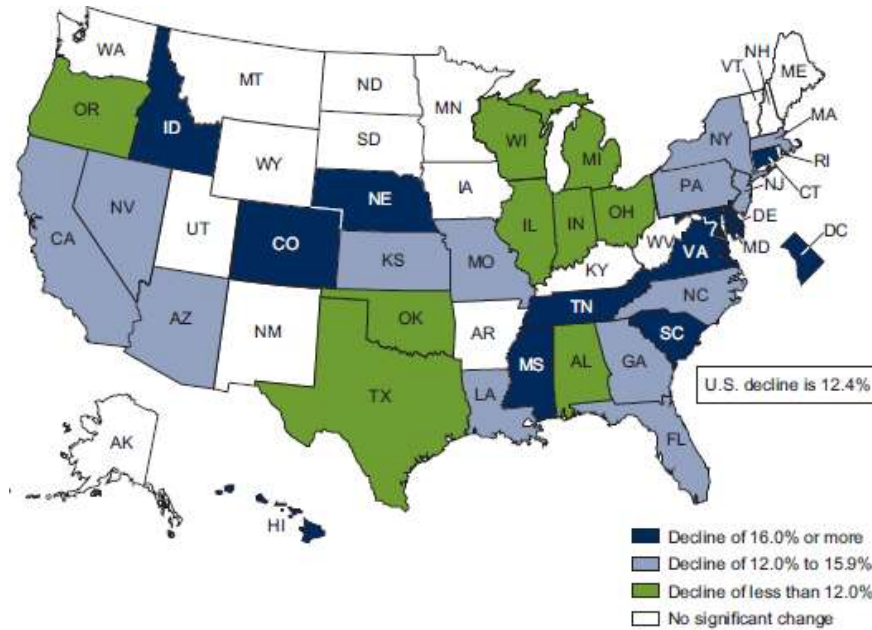
The infant mortality rate (IMR) in Delaware has been decreasing over the last decade as well (Figure 3). From a peak in 2000-2004 of 9.3 deaths/1,000 live births, the Delaware IMR has decreased 19% to 7.5 deaths/1,000 live births in 2010-2014. While the national average percent decline in IMR was 12.4%, Delaware is only one of 11 states in the US with greater than a 16% decrease in IMR since 2005 (Figure 4).⁴ Findings from the FIMR deliberations and collaborative action under the auspices of the Delaware Healthy Mother and Infant Consortium (DHMIC) and the Delaware Perinatal Collaborative address key factors contributing to infant mortality. The racial disparity in IMR, however, persists both in the state and nationally, with the Black IMR (12.1 deaths/1,000 live births) 2.2 times higher than the White rate (5.4 deaths/1,000 live births) in Delaware from 2010-2014 (Figure 3). Also, increasing trends in the number of substance-exposed infants born in the state--mirroring national trends--and the persistence of a high rate of very low birthweight births (<1500 grams) (8.5% of Delaware births compared to a national average of 8.1% of US births) will need to be tackled to continue to make gains in infant health.⁵

Figure 3: Five-year average infant mortality rate (deaths/1,000 live births) in the US and Delaware, by race



Source: Delaware Health Statistics Center, Division of Public Health. Delaware Vital Statistics Annual Report, Infant Mortality 2014. Downloaded from: <http://dhss.delaware.gov/dph/hp/annrepvs.html> on June 20, 2017.

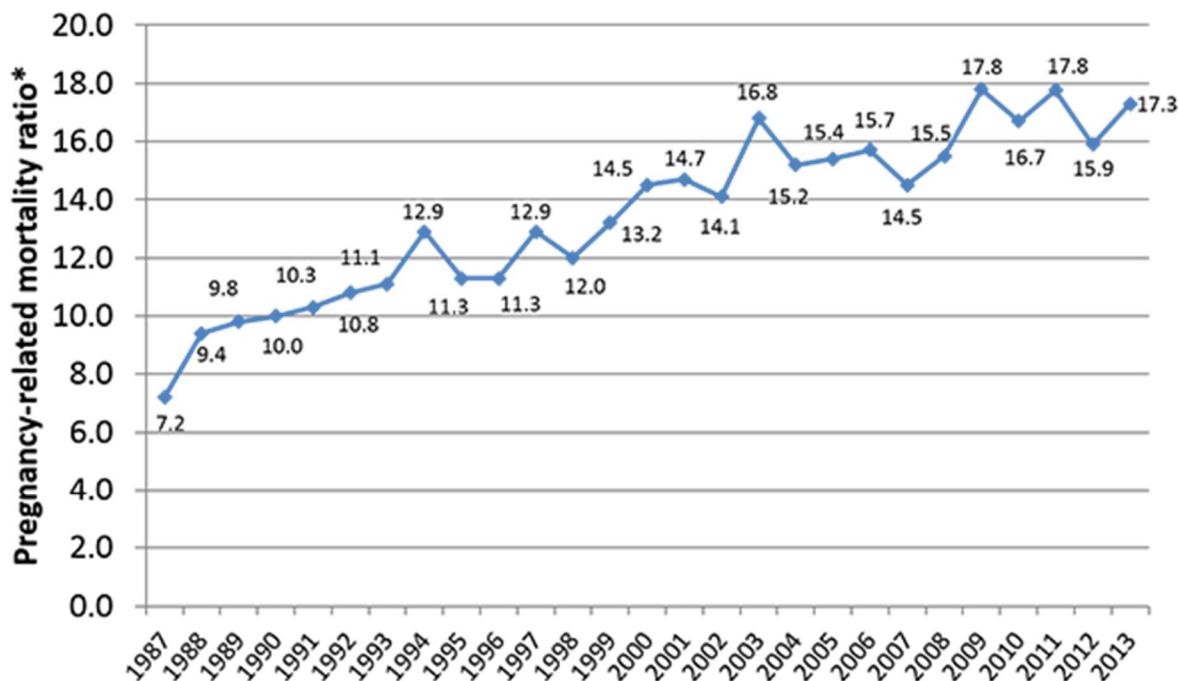
Figure 4: Percent change in infant mortality rate by state, US 2005-2007 compared to 2012-2014



Source: Matthews TJ and Driscoll AK. Trends in infant mortality in the United States, 2005-2014. National Center for Health Statistics (NCHS), CDC. NCHS Data Brief, No. 279, March 2017.

A key maternal child health indicator bearing on the efforts of the CDRC MMR is the pregnancy-related mortality ratio, the number of pregnancy-related deaths per 100,000 live births. Unlike child death rates and IMR which have been trending down, the pregnancy-related mortality ratio has been increasing over the last decade in the US (Figure 5). A pregnancy-related death is defined as the death of a woman while pregnant or within one year of pregnancy—regardless of the duration or outcome of pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.⁶ In Delaware, close collaboration between the CDRC and the CDC has enabled better data standardization to calculate maternal mortality statistics. Delaware’s pregnancy-related mortality ratio for 2009-2015 is slightly higher than the national average at 18 per 100,000 live births.

Figure 5: Trends in pregnancy-related mortality in the US, 1987-2013



*Note: Number of pregnancy-related deaths per 100,000 live births per year.

Source: CDC. Pregnancy mortality surveillance system. Available at:

<https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html>, accessed on June 20, 2017.

In 2016, CDRC panels reviewed a total of 195 CDR, FIMR and MMR cases. The focus of the Commission staff and panel reviews in 2016 was to clear the backlog of older cases so that moving forward more timely reviews can be conducted. To that end, sometimes older cases were administratively closed and processes were put into place to expedite case reviews and standardize data collection across panels. The 195 cases reviewed represent deaths spanning a wide range of years. The range of years of death was widest for child death cases: its 105 cases covered 2004 to 2016, with many of the older cases representing unsolved homicides. Eighty-four FIMR cases dated from 2010 to 2016, and six MMR cases dated from 2012 to 2015. The span of years of death covered obscures temporal trends as does the

small number of cases in a state such as Delaware. Despite these limitations, some key themes and recurring issues emerged from CDR, FIMR and MMR:

1. The underutilization of evidence-based home visiting services
2. The detrimental impact of substance abuse and addiction
3. The risk of multigenerational exposure to social determinants of health such as adverse childhood experiences (ACEs)

These themes are explored in each of the following programmatic sections as they pertain to findings from all three mortality reviews.



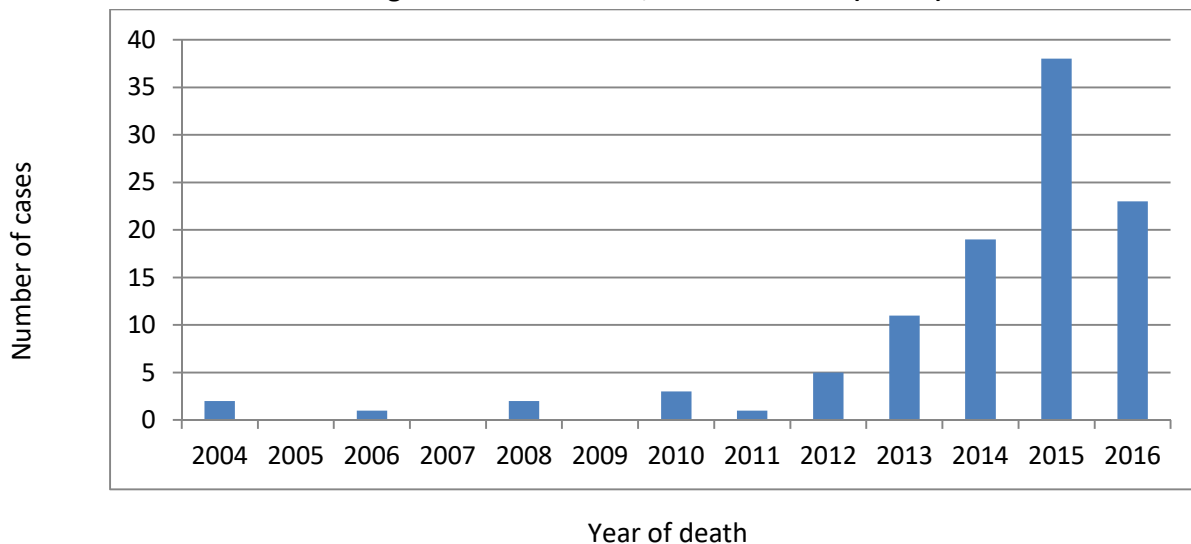
Child Death Reviews

Overview

The CDR panel and Sudden Death in the Young (SDY) panel reviewed 105 cases in 2016, clearing a backlog that dated to 2004. CDR policies were drafted and updated and an internal tracking database was fully implemented to more systematically note data gaps and psychosocial risk factors in each case. In addition, a findings database was implemented in 2016 to track the outcome of panel deliberations and better identify recurring themes from case review. Moving forward in 2017, there will be more concurrent review of CDR cases ideally within six months of the date of death. If there is pending prosecution in the case, the review will be delayed until prosecution is complete or two years has passed, per the policy. If the case is not resolved within two years, aggregate data will be entered into the database and a review will not occur. Also, a medical abstractor will be summarizing medical records for the CDR panel which will likely contribute to better documentation for data surveillance.

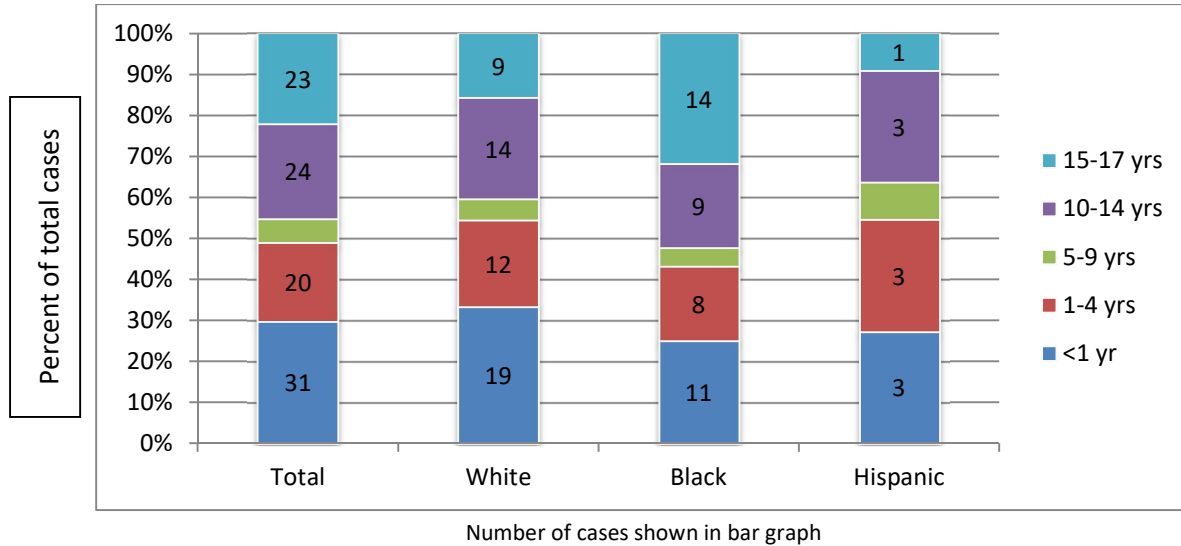
Of the 105 total CDR cases, 26 cases were reviewed by the SDY panel and 79 by the CDR panel. Twenty-three cases were unsafe sleep deaths, and 10 cases were jointly reviewed by the Child Protection Accountability Commission's (CPAC) Child Abuse and Neglect (CAN) panel. Four cases were administratively closed as they involved pending legal proceedings. Most of the 105 cases date from 2014 to 2016 (Figure 6). Over half of CDR cases involved children identified as White (54%, n=57) and 43% involved children identified as Black (n=45). Eleven cases (10%) involved children of Hispanic ethnicity.

Figure 6: Year of death, 2016 CDR cases (n=105)



The age distribution of CDR cases by race is shown in Figure 7. Overall, 30% of CDR cases involved infants below one year of age. CDR panels review infant cases when there is a suspected unsafe sleep death or the death was sudden and unexpected, other causes of infant deaths are triaged to FIMR for review. In 2015, the CDRC was awarded the SDY grant and all suspected unsafe sleep deaths are assigned to the SDY panel. A higher proportion of Black deaths occurred in the 15-17 year age group (31%, n=14) compared to White deaths (16%, n=9). A higher proportion of White deaths reviewed occurred in infancy (33%, n=19) compared to Black deaths (24%, n=11).

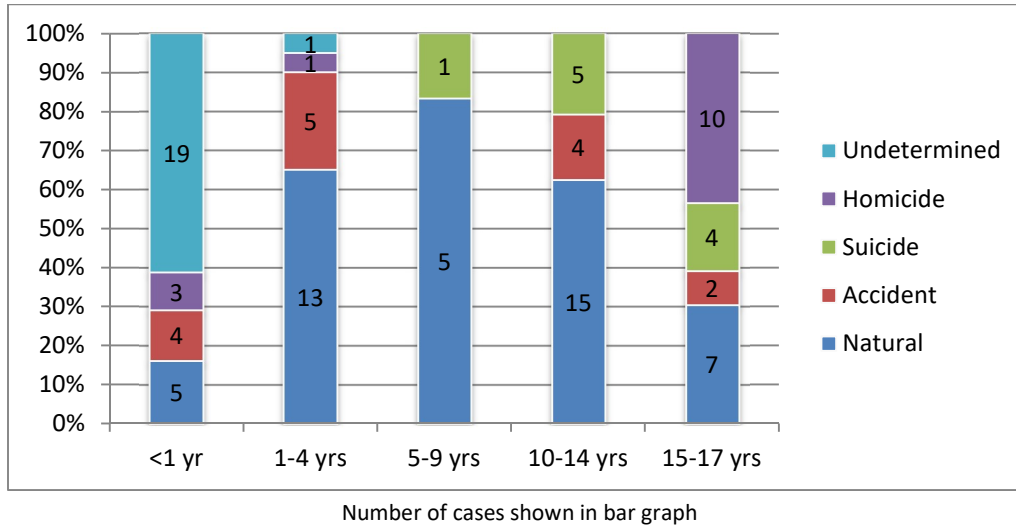
Figure 7: Age distribution of 2016 CDR cases, by race and ethnicity



The cause of death varied by age as shown in Figure 8. Among infant cases, most were deemed undetermined (n=19). Natural causes predominated in the 5-14 year age group. Suicides accounted for 21% (n=5) of the 10-14 year old deaths and 17% (n=4) of the 15-17 year old deaths. Among 15-17 year olds, homicides was the leading cause of death (n=10), representing 43% of cases in this age group. More detailed information and risk factors are discussed in the subsequent sections by cause of death.



Figure 8: Cause of death by age group, 2016 CDR cases



Infant cases: CDR and SDY Findings

Thirty-one infant deaths were reviewed by CDR and SDY panels. Infant deaths due to suspected unsafe sleep are currently reviewed by the SDY panel, whereas other causes of infant deaths are reviewed by FIMR (see FIMR section). Cases of infant homicide are reviewed by the CPAC CAN panel. Table 1 presents some risk factors by manner of death in infancy among cases reviewed by CDR and SDY panels. Nine infants (29%) were born prematurely before 37 weeks gestation, and four infants were low birth weight (<2500 grams). Over half of infants had a history of intrauterine smoke exposure (52%, n=16), and in seven cases (22%) mothers entered prenatal care late. Six infants were born with intrauterine drug exposure (19%). From the CDR internal tracking database, ten mothers tested positive for substances before or at the time of delivery. In 8 of the 10 cases the mother had a documented history of opiate use, and two cases involved cocaine use. Seven infants (22%) who subsequently died underwent neonatal abstinence syndrome (NAS) scoring in the hospital. In 4 of the 10 cases, the Division of Family Services (DFS) was notified due to the history of drug exposure. Six of the 10 substance-exposed infant cases were referred to home visiting or community services such as Child Development Watch. Half of these cases (n=3) enrolled in services. In six cases of infant deaths, there was documented history of All Babies Cry (ABC) education, and another 18 cases had undocumented history of ABC education. In 11 cases there was documentation of safe sleep education, while in 15 cases this history was undocumented.

Table 1: Manner of death, CDR infant cases (n=31)

Manner Of Death					
Category	Natural	Accident	Homicide	Undetermined	Total
Deaths Reviewed	5	4	3	19	31
Premature (<37 Weeks)	1	2	1	5	9
Low Birth Weight (<2500 grams)	0	2	0	2	4
Intrauterine Smoke Exposure	2	2	1	11	16
Intrauterine Alcohol Exposure	0	0	0	1	1
Intrauterine Drug Exposure	1	0	1	4	6
Late (> 6 months) or No Prenatal Care	1	1	0	5	7

Findings to Action: the All Babies Cry® Program

The CDRC, in collaboration with the Children’s Trust of Massachusetts and Prevent Child Abuse Delaware and grant support from the Federal Community Based Child Abuse Prevention Program, are educating parents based on the evidence-based program entitled “All Babies Cry” ® (ABC) to prevent abusive head trauma (AHT). AHT (otherwise known as Shaken Baby Syndrome) is the name for injuries to an infant’s brain caused by vigorous shaking and/or blunt impact. Using the “Strengthening Families” model’s protective factors, ABC goes beyond traditional AHT prevention and additionally aims to enhance new parents’ confidence in soothing their infant and themselves when feeling stressed.

ABC launched on January 1, 2014. Approximately 10,000 new parents each year receive this much-needed information. Staff at each birthing hospital have been trained to introduce the 11-minute in-hospital version of ABC to new parents and families at the maternity bedside. In addition, each family is given the 14-page ABC booklet, which includes hotline numbers, checklists, activities and other resources. Parents can go to a website, which includes over one hour of streaming video of the ABC program. This information is helpful to anyone who will be caring for their newborn, and includes a tip sheet for what soothing techniques can work for the specific newborn. All materials are in English and Spanish with closed captioning. Follow up phone surveys reveal that parents think the program is very helpful in providing strategies to calm their crying infant, as well as helping to understand and manage their stress when the infant is crying (Figure 9). Delaware has witnessed a significant 47% decrease in the incidence of AHT (most include retinal hemorrhages and subdural hematoma) from 2015 to 2016 since All Babies Cry has been introduced to parents in the state.

Figure 9: Parents' survey responses about the All Babies Cry (ABC) program
 (based on 322 respondents)

Note: SBS refers to Shaken Baby Syndrome.

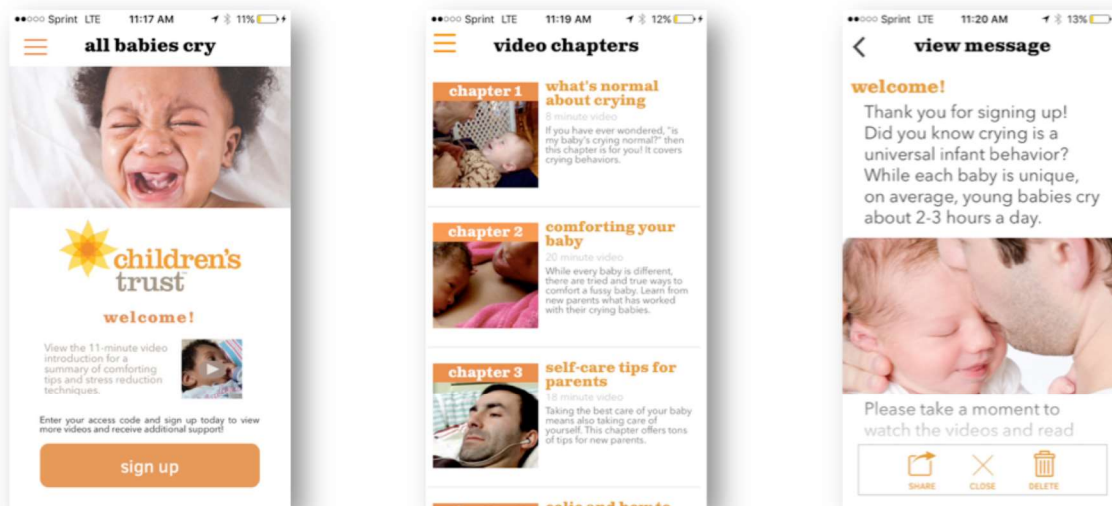
Questions	Percentage
Do you remember a nurse talking to you about SBS after you had your child?	75%
When you came home from the hospital did you access the All Babies Cry booklet?	46%
Did you find the booklet helpful? (Y/N)	56%
Did the booklet improve your knowledge of infant crying?	47%
Did the booklet give you strategies to calm your crying infant that you used?	48%
Did the booklet help you understand and manage your caregiver stress when your infant cries?	49%
Has your partner ever visited or used the All Babies Cry literature or website? (Yes, literature/website or No)	44%

Results from Delaware's All Babies Cry Questionnaire 2016



Figure 10: Mobile app and promotional materials developed for the Delaware ABC program, available at <http://www.allbabiescry.com/>, password DEBABY

mobile app



Joint Committee on Substance-Exposed Infants and Medically Fragile Children

The Joint Committee on Substance-Exposed Infants and Medically Fragile Children was established in 2015 by CPAC and CDRC with the following charge:

- a) To establish a definition of the medically fragile child, inclusive of drug-exposed/addicted infants;
- b) To draft a statute to mirror the definition as needed and consider adding language to the neglect statute;
- c) To recommend universal drug screenings for infants in all birthing facilities in the state;
- d) To review and revise the DFS Hospital High Risk Medical Discharge Protocol to include all drug-exposed and medically fragile children. The protocol shall include: responding to drug-exposed infants and implementing the Plan of Safe Care per the Child Abuse Prevention and Treatment Act (CAPTA), involving the multidisciplinary team in ongoing communication and collaboration for medically fragile children, referring medically fragile children to evidence-based home visiting programs prior to discharge, and reviewing and including the Neonatal Abstinence

Syndrome (NAS) Guidelines for Management developed by DHMIC's Standards of Care Committee.

The Joint Committee on Substance-Exposed Infants/Medically Fragile Children continued to meet throughout 2016 to review and implement the recommendations from the May 2015 Action Plan. In doing so, the Committee identified present concerns with the cross-system response to substance-exposed infants that were promptly addressed, such as universal screening of all pregnant women at the time of delivery and the implementation of DFS substance abuse liaison referrals. The Committee has also worked with system partners to identify concerns that will need long term attention, such as the drafting of state legislation and the implementation of plans of safe care. Ultimately, the Committee acknowledged that the best intervention to protect substance-exposed infants and to provide treatment and services to their families consists of a multidisciplinary team effort. To this end, an application for In-Depth Technical Assistance for Substance-exposed Infants was submitted to the National Center on Substance Abuse and Child Welfare and granted to the State of Delaware.⁷ The technical assistance began in September 2016 and will convene a training for the core team in February 2017.

The importance and relevance of the work of the Joint Committee is underscored by the rising number of substance-exposed infant cases identified: 2016 saw a 47% increase in the number of substance-exposed infants, from 294 cases in 2015 to 431 cases in 2016. Seventy-two percent of the 2016 cases were screened in by DFS, and in 20% the mother had a prior history of a substance-exposed infant. CDRC and CPAC will continue their work in the Joint Committee to champion the passage of a state law, implement the federal law for reporting substance-exposed infants, and develop a multidisciplinary plan of safe care.

Sleep-Related Deaths

Twenty-two infant cases were sleep-related deaths, half of which (n=11 cases) occurred under one month of age. One sleep-related death occurred outside of infancy, in early childhood, involving a child who was born premature. Thus there were a total of 23 sleep-related deaths reviewed in 2016. Fifty-seven percent of sleep-related deaths involved White children (n=13) and 39% involved Black children (n=9). Table 2 lists the causes of death in sleep-related cases. Other causes of death included one homicide.

Table 2: Cause of death, sleep-related cases reviewed (n=23)

Primary cause of death	Number of cases
Undetermined	7
Sudden Unexplained Death in Infancy (SUDI)	7
Positional asphyxia	3
Anoxic encephalopathy	3
Other	3

Risk factors identified in sleep-related deaths are presented in Table 3. Eighteen infants were not sleeping in a crib or bassinette despite the fact that two cases involved families who were Cribs for Kids recipients. However, these families had extensive psychosocial issues that despite the education may have impacted their ability to follow medical advice. Fifteen infants were co-sleeping, and in six cases the adult caregiver was drug impaired. Eleven infants (50%) were found not sleeping on their back. This high prevalence suggests that continued work on safe sleep education and safe sleep positioning is needed. According to the CDR internal database, 7 cases of sleep-related deaths involved infants with known substance exposures, including opiate exposure (n=6) and cocaine exposure (n=2). Safe sleep education was documented in 10 of the 23 sleep-related death cases. In two cases this education was not documented, and in 11 cases education status was unknown.

Table 3: Factors identified in sleep-related deaths (n=23)

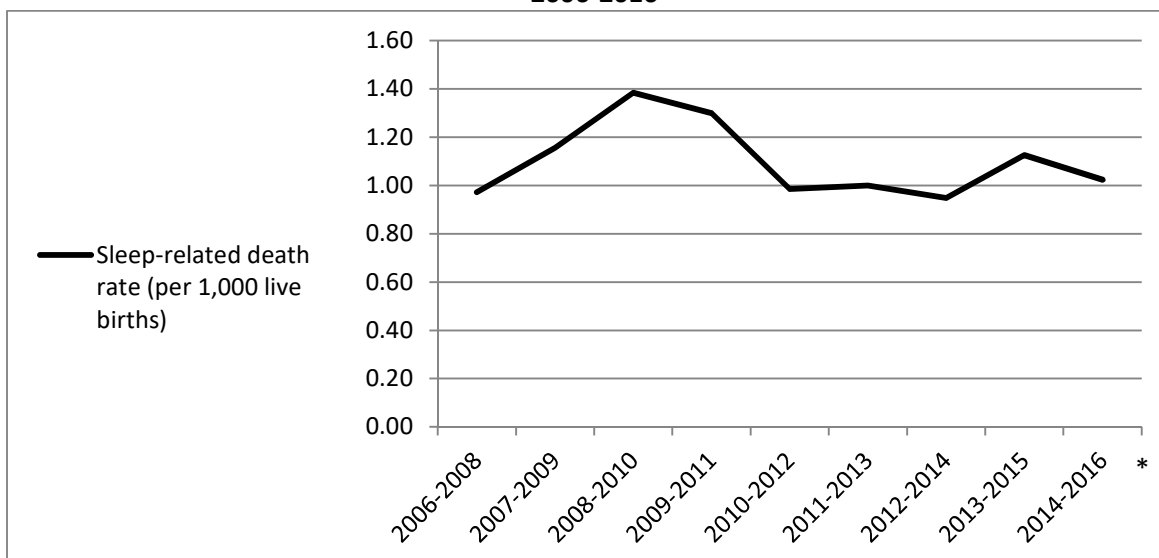
Factor	Age Group							Unknown	Sub Total
	0-1 Months	2-3 Months	4-5 Months	6-7 Months	8-11 Months	1-4 Years	5 Years and Up		
Deaths Reviewed	11	6	3	0	2	1	0	0	23
Not in a crib or bassinette	9	4	3	0	1	1	0	0	18
Not sleeping on back	5	5	0	0	0	1	0	0	11
Unsafe bedding or toys	0	0	0	0	0	0	0	0	0
Sleeping with other people	8	4	3	0	0	0	0	0	15
Obese adult sleeping with child	0	1	0	0	0	0	0	0	1
Adult was alcohol impaired at time of death	2	0	0	0	0	0	0	0	2
Adult was drug impaired at time of death	3	0	2	0	0	1	0	0	6
Caregiver/Supervisor fell asleep while bottle feeding	1	1	1	0	0	0	0	0	3
Caregiver/Supervisor fell asleep while breast feeding	2	0	0	0	0	0	0	0	2

Trends in Data: Delaware Sleep-related Deaths

CDR panels have been reviewing sleep-related deaths and reporting annually on associated risk factors. Trends in the rate of sleep-related deaths reflect some random fluctuation as a result of the small

number of cases and live births in Delaware. Figure 11 shows the three-year average sleep-related death rate per 1,000 live births in Delaware from 2006 to 2016. The sleep-related death rate peaked in 2008-2010 at 1.38 deaths per 1,000 live births and since then has gradually been decreasing to 1.02 deaths per 1,000 live births in 2014-2016. While not all sleep-related deaths occur in infancy, the vast majority do. CDRC data shows that among 96 sleep-related death cases reviewed between 2006 and 2016, 97% (n=93) occurred under one year of age. The remaining 3% (n=3 cases) occurred in the 1-4 year age group. In infancy, Delaware data shows that 21% of cases occurred under one month of age, and the peak incidence (45% of cases) occurred between 2 and 3 months of age.

Figure 11: Three-year average rate of sleep-related deaths in Delaware (per 1,000 live births), 2006-2016



*The number of live births in 2016 has not yet been released, so the number of live births in 2015 was used as the 2016 count.

Findings to Action: The Infant Safe Sleeping Program Community Action Team (TISSPCAT)

Mission Statement:

To reduce the number of SIDS and SUID cases in the State of Delaware through educational awareness campaigns around safe sleeping practices.

Goals:

- Expand message from “Back to Sleep” to the safe sleep environment that will include all of the American Academy of Pediatrics’ (AAP) task force recommendations on safe sleep practices.
- Reinforce messages wherever and whenever possible.
- Ensure messages are consistent and make sense to the lay public.
- Ensure messages address parental desire to keep baby safe and comfortable.
- Ensure messages emphasize parental self-efficacy and the preventability of infant unsafe sleeping death.

The Infant Safe Sleeping Practice Subcommittee was created by the CDRC in 2006 after the Commission reviewed a total of 57 infant sleep-related deaths. In 2012, the Committee switched its focus and became an action committee. Therefore, the name was changed from the Infant Safe Sleeping Practice Subcommittee to the Infant Safe Sleeping Practice Community Action Team (TISSPCAT). The mission of TISSPCAT is to reduce the number of SIDS (Sudden Infant Death Syndrome) and SUID (Sudden Unexplained Infant Death) cases in the State of Delaware through educational awareness campaigns around safe sleeping practice. TISSPCAT collaborates with many other agencies in the state who are also interested in reducing the number of unsafe sleep deaths.

TISSPCAT activities during 2016 have included the following:

- Reviewing infant safe sleep regulations for DFS and for the Office of Child Care Licensing.
- Teaching at the Delaware Adolescent Program, Inc. (DAPI), New Expectations (a group home for pregnant offenders with substance abuse issues) and daycare facilities.
- Updating the online training safe sleep program for daycare providers through the Department of Human Development & Family Studies at the University of Delaware.
- Presenting at hospital Grand Rounds.
- Consulting with the DHMIC and their media agency on Delaware's infant safe sleep messaging.
- Consulting with the Cribs for Kids Program® which includes training for all agencies wishing to participate in the program. To date over 1,500 Pack 'n Plays have been distributed to needy families in the state.
- Organizing community baby showers.
- Providing safe sleep certification for all hospitals in the state.
- Continued support of the Direct on Scene Education (DOSE) program and Cops 'n Kids.
- Consulting with the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) and Collaborative Innovation and Improvement Network programs.
- Continued work with the Nemours primary care offices on the "Sleep Baby, Safe and Snug" book research project.
- Participating with the American Society for Testing Material and the Consumer Product Safety Commission in developing standard consumer safety specifications for baby boxes.
- Organizing educational table displays at the "I Love Smyrna Day" and the DHMIC annual summit.

Future TISSPCAT plans include the distribution of the "Sleep Baby, Safe and Snug" book to every family delivering in the state for one year.

Motor Vehicle Deaths

There were five motor vehicle deaths reviewed in 2016. All children involved were White; three deaths occurred in a suburban area and two deaths in a rural area. One child was an infant, and the other four children were 10 to 17 years of age. One death involved the driver, three deaths involved passengers, and one death was a pedestrian. In the three passenger deaths, contributing factors identified by the CDR panel were: improper use of a child seat (n=1), lack of use of a lap belt (n=1) and lack of use of a shoulder belt (n=1).

Fire Deaths

Four fire deaths were reviewed in 2016. The children were between 0 and 4 years of age at the time of death. Two were White and two were black. Two cases were deemed accidental deaths, and two were deemed homicides.

Drowning Deaths

Three drowning deaths were reviewed in 2016 involving children between the ages of 1 and 4 years. The CDR panel noted that in all three cases the child was not being supervised at the time of the incident and in two cases there was no barrier to the water.

Poisonings and Overdoses

Four cases of poisonings and overdose deaths were reviewed: one involved an infant and the other three cases involved children 10 to 17 years of age. Prescription drugs were implicated in all four cases and over the counter drugs in two cases. Factors identified at the time of case review are summarized in Table 4.

Table 4: Factors involved in poisonings and overdose deaths (n=4)

Incident resulted from	Deaths reviewed	Prescription drug	Over the counter drug	Other
Accidental overdose	1	1	0	0
Deliberate poisoning	3	3	2	1
Storage of substance				
Open area	1	1	1	0
Open cabinet	1	1	1	0
Other circumstances				
Poison control was called	0	0	0	0
Child not supervised, but should have been	1	1	1	0
Supervisor speaks English	3	3	2	0

Weapons-related Deaths

Thirteen weapons-related deaths involving males were reviewed in 2016. Eleven were deemed homicides, and two were suicides. Ten cases involved Black children and three cases involved White children. Eleven deaths—including the two suicides—were a result of firearms, nine of which were handguns. Rope and physical force were the means of the other two deaths. In one firearm case, the weapon was stolen; in two cases the child's parent was the owner of the firearm. Table 5 reports the use of the weapon at the time of the incident. Notably, seven deaths were due to gang-related activity.

Table 5: Use of weapon at time of incident (n=13)

Leading Uses of Weapon at Time of Incident	Firearm	Person's Body Part	Rope	Total
Self-Injury	2	0	0	2
Other	0	1	0	1
Commission of Crime	2	0	0	2
Argument	1	0	0	1
Playing with Weapon	0	0	0	0
Gang-related activity	7	0	0	7
Random Violence	1	0	1	2
Drive-by shooting	5	0	0	5
Intimate partner violence	0	0	0	0
Child was a bystander	2	0	0	2

There was a high prevalence of psychosocial risk factors among the victims of the assault and the perpetrators, when that person was known. Risk factors prevalent among the victims include a history with DFS, evidence of domestic or family violence, and criminal history (Table 6). Four of the victims had a history of substance abuse, and two were drug or alcohol impaired at the time of the incident. Among the perpetrators, two had a history of substance abuse, three had a history of intimate partner violence (IPV) as the perpetrator, and one had a history of child abuse as the perpetrator.

Table 6: Psychosocial factors identified among assault victims (n=13)

Child History	Caused	Contributed	Total
History of substance abuse	4	0	4
Drug/alcohol impaired at time of incident	2	0	2
History of mental illness	0	0	0
Had transgendered identity	0	0	0
Was gay/lesbian/bisexual/questioning	0	0	0
Criminal history or delinquency	6	0	6
Spent time in juvenile detention	6	0	6

CPS Involvement	Caused	Contributed	Total
Open CPS case at time of death	1	1	2
Investigation found evidence of prior abuse	5	1	6
Child had history of maltreatment as victim	6	1	7
Child placed outside of home	6		6
History of intimate partner violence as victim	3	1	4
History of intimate partner violence as perpetrator	0	0	0
CPS action taken because of death		1	1

Suicide Deaths

Ten deaths reviewed in 2016 were suicides: one child was 5-9 years old, five were 10-14 years old, and four were 15-17 years old. Eight deaths involved males and two involved females. Seven White children and three Black children committed suicide. Five deaths were by means of hanging, two deaths were by firearms, two deaths were a result of deliberate overdoses, and one impact injury. Eight children (80%) had a history of child maltreatment as a victim, and five had a DFS investigation substantiate evidence of prior abuse (Table 7). Other risk factors in the child’s psychosocial history and circumstances around the time of the suicide are also listed in Table 6. Three children had a history of mental illness, and four were receiving treatment for mental health conditions at the time of their death. Two children had a history of substance abuse, and one child had made a prior suicide attempt. Precipitating factors that may have contributed to the suicides include: parents’ divorce or separation (30%), argument with parents or caregivers (30%), serious school problems (30%), rape/sexual abuse (30%), school failure (20%), victim of bullying (20%) and drug or alcohol problem (10%).

Table 7: Risk factors and psychosocial history among suicide cases (n=10)

Child History	Caused	Contributed	Total
History of substance abuse	2	0	2
Drug/alcohol impaired at time of incident	3	0	3
History of mental illness	3	0	3
Had transgendered identity	0	0	0
Was gay/lesbian/bisexual/questioning	1	0	1
Criminal history or delinquency	3	0	3
Spent time in juvenile detention	1	0	1
CPS Involvement	Caused	Contributed	Total
Open CPS case at time of death	1	0	1
Investigation found evidence of prior abuse	5	0	5
Child had history of maltreatment as victim	8	0	8
Child placed outside of home	2	0	2
History of intimate partner violence as victim	1	0	1
History of intimate partner violence as perpetrator	1	0	1
CPS action taken because of death	4	0	4

Social Determinants of Health: Pertinent CDR and SDY Findings

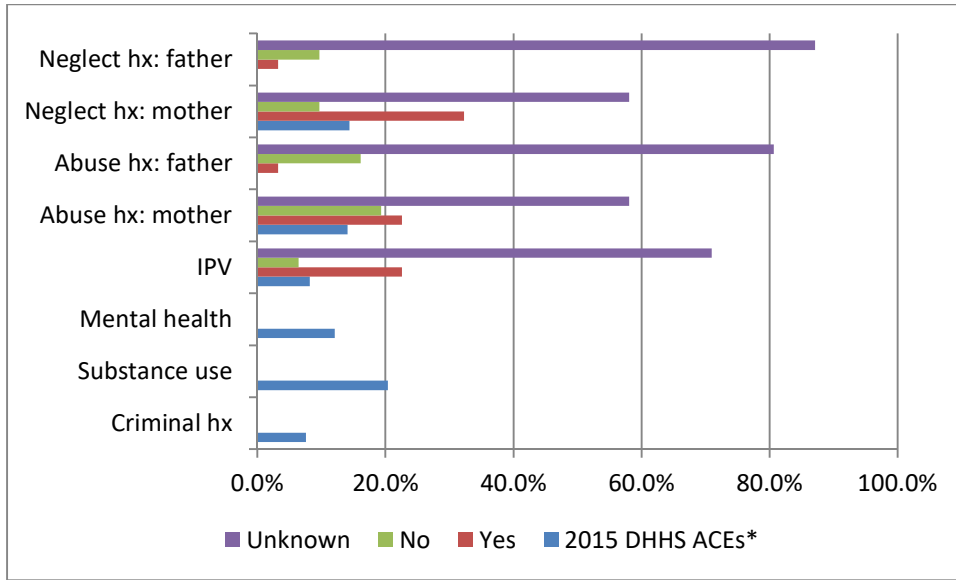
In 2016 psychosocial factors were collected prospectively on cases and tracked in the internal CDR database. Table 8 presents the proportion of cases with DFS history reported separately for infant CDR cases (age ≤ 1 year at time of death, n=31) and non-infant cases (n=74). A higher proportion of infant cases was active with DFS at the time of death (19%) and had any family history/multigenerational history with DFS (77%) compared to non-infant cases (5% and 53%, respectively). For both groups, the majority of CDR cases (60%) did have a family history of DFS contact.

Table 8: DFS history in CDR cases, for infants and children above one year of age

	Active with DFS at time of death	Active with DFS within 12 months of death	Family history with DFS
Infant cases (n=31)	19%	26%	77%
Non-infant cases (n=74)	5%	14%	53%

History of maternal or paternal intimate partner violence (IPV), history of abuse (physical or sexual) in the mother or father’s childhood, and their history of neglect (physical or emotional) during childhood were also tracked. In the majority of CDR cases, infant as well as non-infant cases, these ACE factors were not known for the mother or father of the deceased child (Figures 12 and 13). In about 80% of cases, paternal history of abuse or neglect was not known. Maternal history of abuse or neglect was not known in 58% of infant cases and about 70% of non-infant cases. Even with these large gaps in the completeness of the data, there was a high prevalence of a history of maternal neglect, maternal abuse and IPV among infant cases compared to the 2015 Delaware Household Health Survey (DHHS) ACEs study (Figure 12). In the Delaware ACEs study, 14% of adults had a history of abuse and 14% had a history of neglect. Among mothers whose infants died in the CDR cohort, 23% had a history of abuse and 32% had a history of neglect. IPV history was found in 8% of Delaware adults surveyed, but was much higher among infant cases, with a prevalence of 23%. Among non-infant CDR cases, gaps in paternal and maternal history were greater. In this group, only the history of IPV, which was documented in 16% of cases, was higher than the Delaware ACEs study finding of 8% (Figure 13). These findings suggest that ACEs are not only a risk factor for mothers, but also a risk factor for their infants and thus have multigenerational impact. It should be noted that the CDR cases for which ACE history was known are more likely to be cases with a DFS history as well, so there is likely ascertainment bias, and thus the findings should be interpreted with caution. In the future, more complete data on ACEs should be sought and factors relating to maternal and paternal mental health, substance use and criminal history tracked.

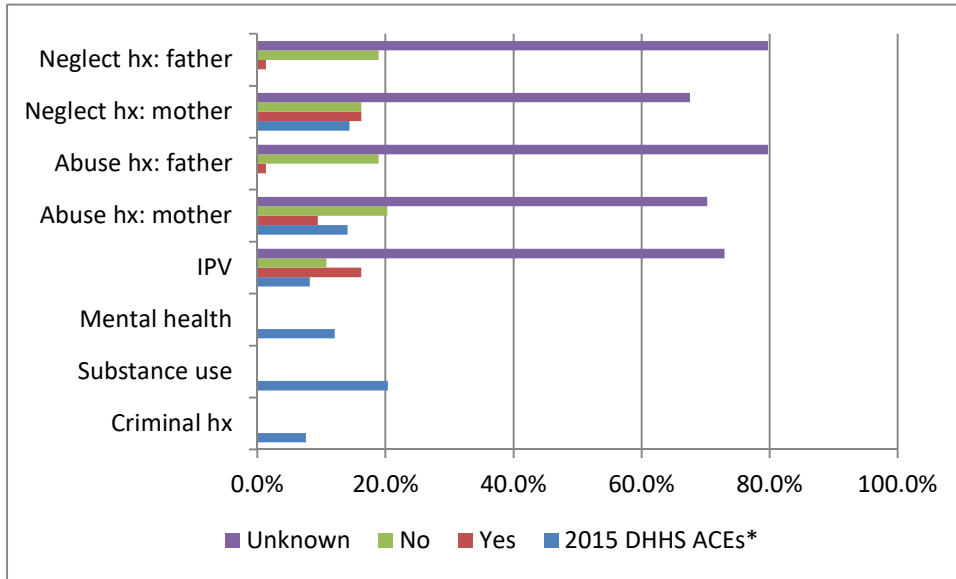
Figure 12: Adverse Childhood Experiences (ACEs): prevalence in CDR infant cases (n=31)



Hx=history

*Torrance CA, et al. Adverse childhood experiences negatively impact health behaviors and chronic disease risk among adults residing in Delaware, DE J Public Health 2016.

Figure 13: Adverse Childhood Experiences (ACEs): prevalence in CDR non-infant cases (n=74)



Hx=history

*Torrance CA, et al. Adverse childhood experiences negatively impact health behaviors and chronic disease risk among adults residing in Delaware, DE J Public Health 2016.

Substance Abuse: Pertinent CDR and SDY Findings

Among CDR infant cases, 19% of infants (n=6) had a history of intrauterine drug exposure and 21% of infants were evaluated for NAS based on maternal history. The rate of NAS among all live births in Delaware in 2013 was 18.5/1,000 live births, or about 1.8%.⁸ Thus the risk of NAS and drug exposure is about 10 times higher in infant death cases.

Alarming high risk of substance exposure or abuse was also found in other subgroups of child death cases reviewed:

- Among infant unsafe sleep deaths, 26% of adults were drug impaired at the time of the incident.
- Among suicide deaths, 30% (n=3 out of 10) teens were drug or alcohol impaired at the time of the incident.
- 15% of assaults involved drugs or alcohol use.

These trends will continue to be followed and will hopefully continue to galvanize support for the expansion of substance abuse prevention and treatment options in the state.

Home Visiting: Pertinent CDR and SDY Findings

Many evidence-based home visiting programs—such as Nurse Family Partnership and Healthy Families America—focus on the prenatal and infancy period. For that reason, the prevalence of referral to home visiting programs was only accessed for infant deaths. Among this group of 31 cases reviewed, only six cases (19%) were referred to home visiting or community-based services, including Child Development Watch. Of those families referred, half enrolled in the program.

Child Death Review Recommendations

CDRC recommendations in 2016 addressed issues of water safety and erecting appropriate barriers to prevent drownings and explored family notification for risk assessment based on a child's cause of death. The CDRC put forth some additional recommendations based on the review of a few cases that revealed similar issues. These cases involved children with chronic medical conditions that were poorly controlled and for which there were inadequate school action plans. The CDRC recommended:

- The CDRC will develop a subcommittee to explore the issue of action plans and procedures within the schools. Members shall include a designee from the following:
 - a. Delaware American Academy of Pediatrics
 - b. Department of Education
 - c. Delaware School Nurses Association
 - d. CDRC Commissioner (Dr. Margaret Rose Agostino, Chair)

The first meeting of the Subcommittee for Chronic Health Conditions took place in December 2016. The goals for this subcommittee in 2017 are to add additional members as needed to the subcommittee,

research national legislation for health conditions in schools, and evaluate Delaware’s laws and regulations for adequacy.

The CDRC also recommended that the Division of Forensic Science, in collaboration with the CDRC, explore pursuing legislation requiring autopsies for all child deaths that are sudden and unexpected.

Collaboration with the Child Protection Accountability Commission (CPAC)

The CDRC and CPAC met jointly for a retreat on September 15, 2016. The retreat was convened to review the findings and recommendations resulting from the review of child death cases and near death cases due to abuse and neglect. The Commissions were updated on the 18 prioritized systems recommendations stemming from the joint meeting in January 2015. Since approval and implementation of the Action Plan in May 2015, the Commissions have made significant progress with its priority areas for fiscal year 2016.

A new action plan was developed to address the following system areas for the upcoming year: legal, medical, multidisciplinary response/criminal investigations, risk assessment/caseloads, safety/use of history/supervisory oversight, and unresolved risk. The findings in these system areas stem from the review of 41 child abuse and neglect death and near death cases for incidents that occurred between January 2015 and May 2016. The result was 303 findings across six system areas. Thirty-one recommendations for systems improvement are articulated in the action plan. Updates to the action plan will occur at the Commission meetings as progress is implemented on the action plan. Further collaboration with CPAC will occur in the future as the CDRC continues to improve its data collection and compiles findings.



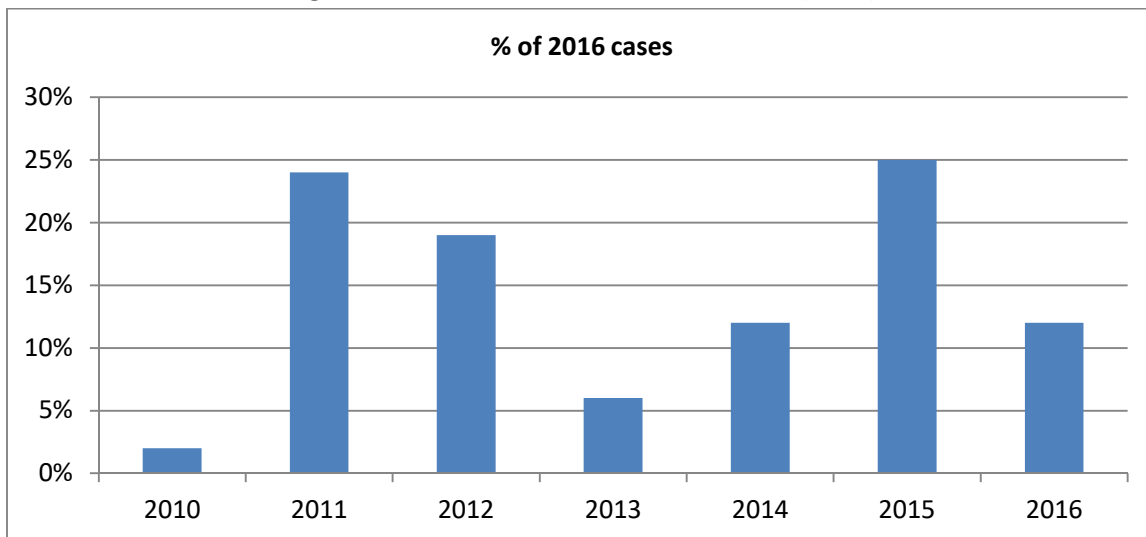
Fetal and Infant Mortality Review

Overview

2016 marked the first year of implementation of the National FIMR (NFIMR) database. This database, managed by Michigan Public Health Institute (MPHI) and the National Center for Fatality Review and Prevention (NCFRP), will help standardize the collection of comparable data across FIMR programs nationwide. Delaware was one of the first FIMR programs to adopt the NFIMR database. The FIMR Program Coordinator is serving on a work group to refine and revise the next version of the NFIMR database due out in early 2018. In addition, CDCR staff continued to use an internal tracking database to collect more Delaware-specific information, particularly relating to ACEs, maternal substance use history, DFS history and other tracking themes identified in prior years of review.

CDCR staff focused on reducing the backlog of older cases in 2016. For FIMR this meant administratively closing 160 cases that dated from 2011 to 2015. This allowed FIMR case review teams (CRTs) to focus on 2016 cases by the latter half of that year. Figure 14 presents the years of death of the 84 FIMR cases reviewed in 2016. Cases date from 2010 to 2016. The 84 cases represent 80 mothers and include four sets of twins. About one-third of cases (34%, n=27) had a maternal interview. Ten mothers (13%) had a history of a previous loss.

Figure 14: Year of death, 2016 FIMR cases (n=84)



Demographic characteristics of the cohort of FIMR mothers are shown in Table 9. For comparison, the demographics of all mothers giving birth in Delaware in 2014, the total infant deaths occurring in Delaware in 2014, and the total fetal deaths occurring in 2013 are also shown. Compared to the live birth cohort, all the other groups—including FIMR mothers—have a larger proportion of Black mothers. Fifty-eight percent of FIMR mothers were White, 39% were Black and 14% were Hispanic. Three-quarters of FIMR mothers received prenatal care beginning in the first trimester, and 5% did not receive

prenatal care. Half of FIMR mothers were on Medicaid at the time of delivery, similar to the proportion of total mothers on Medicaid who had live births in 2014.

Table 9: Maternal characteristics, 2016 FIMR cases (n=80 mothers)

	% FIMR mothers (n=80)	DE live births 2014 (n=10,934) ¹	DE infant deaths 2014 (n=74) ¹	DE fetal deaths 2013 (n=55) ²
Race				
White	58%	66%	51%	44%
Black	39%	27%	41%	47%
Other	1%	7%	8%	9%
Hispanic	14%	14%	Not reported	9%
No information	3%			0%
County				
New Castle	71%	59%	66%	55%
Kent	18%	21%	18%	31%
Sussex	9%	20%	16%	15%
Maternal Age				
< 20 years	3%	6%		7%
20-29	59%	51%		*
30-39	34%	40%		*
40+	5%	3%		*
Maternal Education				
< 12 years	16%	17%		15%
High school/GED	45%	24%		33%
College 1-3 years	14%	28%		20%
College 4+ years	18%	31%		33%
No information	8%	1%		0%
Prenatal care entry				
1st trimester	78%			
2nd trimester	13%			
3rd trimester	3%			
No prenatal care	5%			
No information	3%			
Payment				
Medicaid	51%	46%		
Private	38%	48%		
Self-pay	4%	2%		
Other	11%	3%		

¹Delaware Vital Statistics Annual Report 2014. Downloaded from: <http://dhss.delaware.gov/dph/hp/2014.html> on March

13, 2017.

²Delaware Vital Statistics Annual Report 2013. Downloaded from: <http://dhss.delaware.gov/dph/hp/2013.html> on March 13, 2017.

*categories not comparable

Infant deaths comprised just over half of the 84 FIMR cases reviewed in 2016 (55%, n=46), and 45% (n=38) were fetal deaths. FIMR infants cases had a significantly higher proportion of very premature ages, 72% were less than 28 weeks gestation compared to 47% of fetal deaths (Table 10). Fetal deaths reviewed had a significantly higher proportion of third trimester ages, 29% were between 28 and 36 weeks gestation. Full term cases accounted for 20% to 24% of the infant deaths and fetal deaths, respectively. Figure 15 shows the relative gestational age distributions of FIMR infant and fetal death cases. Figure 16 shows the relative birthweight distributions of FIMR infant and fetal death cases; the difference in birthweight distributions was not statistically significant between these two groups.

Table 10: Fetal and infant characteristics, 2016 FIMR cases (n=84)

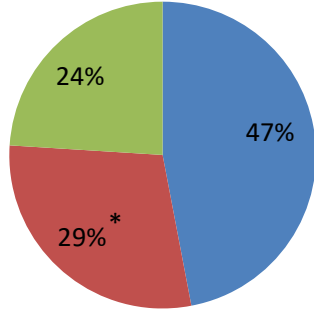
	% total FIMR cases (n=84)	% fetal deaths (n=38)	% infant deaths (n=46)	% DE infant deaths 2009-2013 (n=422) ¹
Sex of fetus or infant				
Male	51%	50%	52%	55%
Female	48%	47%	48%	45%
Plurality				
Single	89%	97%	83%	85%
Multiple gestation	11%	3%	17%	15%
Gestational age (weeks)				
< 28	61%	47%	72%	*
28-36	18%	29%	9%	*
37+	21%	24%	20%	29%
Birthweight (grams)				
< 500	30%	24%	35%	29%
500-1499	38%	37%	39%	31%
1500-2499	14%	21%	9%	12%
2500+	18%	18%	17%	27%

¹Delaware Vital Statistics Annual Report 2014. Downloaded from: <http://dhss.delaware.gov/dph/hp/2014.html> on March 13, 2017.

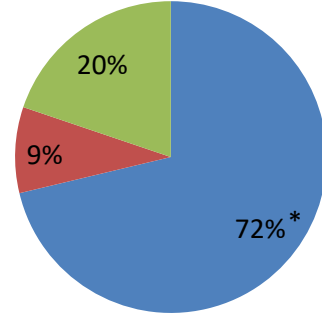
*categories not comparable

Figure 15: Gestational age distribution of FIMR fetal and infant cases

Fetal deaths (n=38)



Infant deaths (n=46)

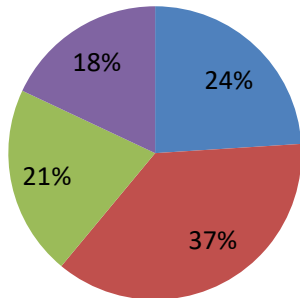


■ <28 weeks ■ 28-36 weeks ■ 37+ weeks

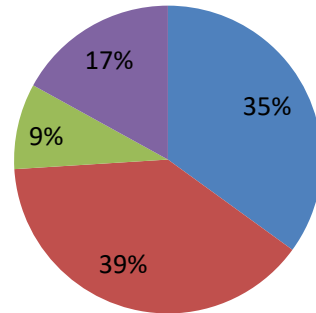
*These differences are statistically significant

Figure 16: Birthweight distribution of FIMR fetal and infant cases

Fetal deaths (n=38)



Infant deaths (n=46)



■ <500 g ■ 500-1499 g ■ 1500-2499 g ■ 2500+ g

Eight-four percent of FIMR infant cases (n=39) were neonatal deaths, occurring before 28 days of age; and 17% of cases occurred in the first day of life (Table 11). A disproportionately high number of FIMR infant cases were due to prematurity, which was listed as the primary cause of death in 67% of cases. In comparison, prematurity was the primary cause of death in only 25% of all infant deaths occurring in Delaware between 2009 and 2013 (Table 12). Any infant deaths suspected to be due to unsafe sleep conditions were reviewed by the CDR or SDY panel, not FIMR.

Table 11: Age at death, FIMR infant cases (n=46)

Age at death	% infant deaths (n=46)
< 24 hours	17%
1-28 days	67%
29-365 days	15%

Table 12: Primary cause of death, FIMR infant cases (n=46) compared to all Delaware infant deaths over five years

Cause of Death	% infant deaths (n=46)	% DE infant deaths 2009-2013 (n=422) ¹
Prematurity	67%	25%
Congenital	17%	15%
Infection	7%	4%
Respiratory distress	2%	4%
Other	7%	

¹Delaware Vital Statistics Annual Report 2014. Downloaded from: <http://dhss.delaware.gov/dph/hp/2014.html> on March 13, 2017.

FIMR Findings

Mothers' medical issues

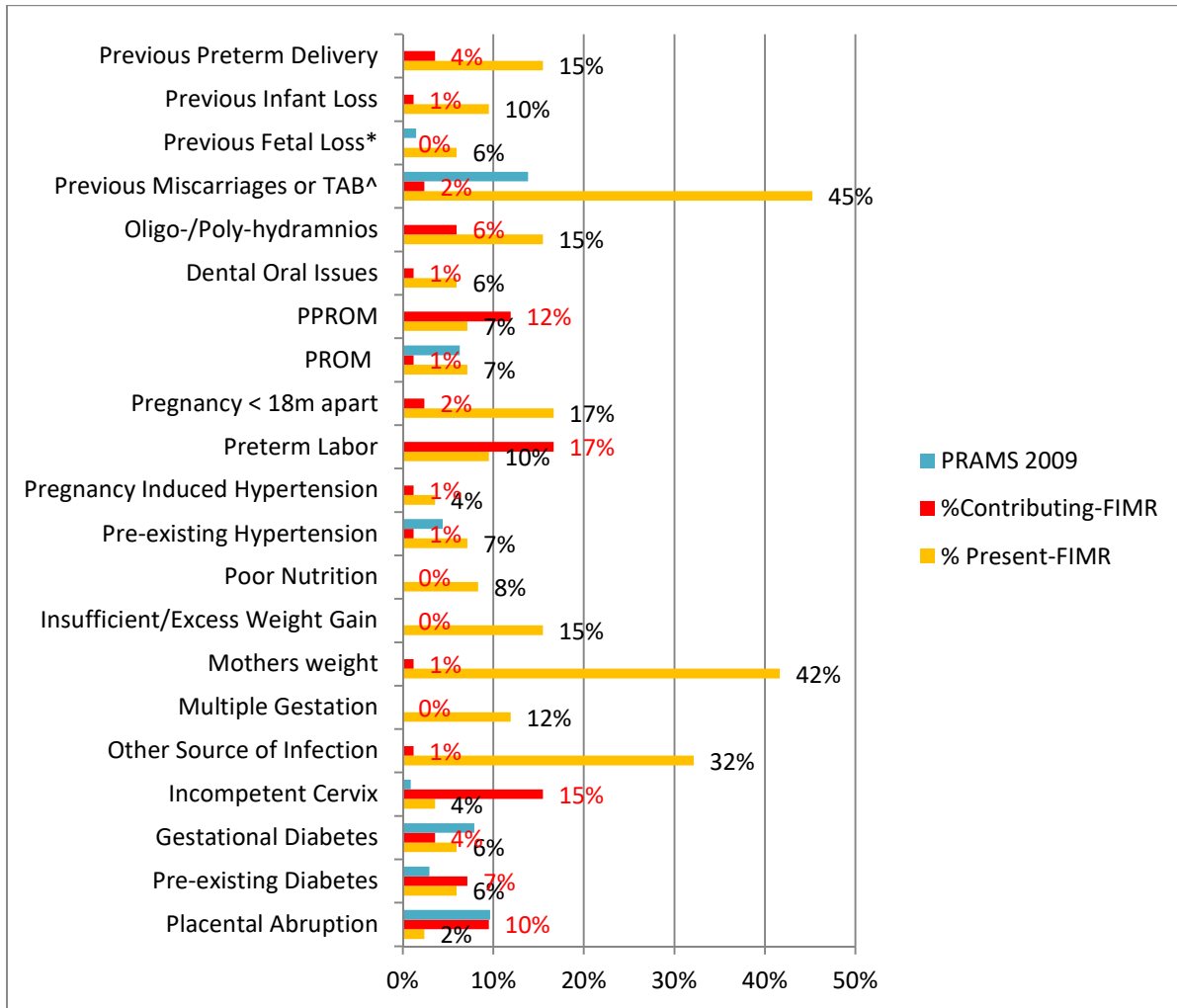
Maternal medical history is collected in the NFIMR database and CRTs reviewing the case must determine whether the medical issue is present in a case but did not likely contribute to the outcome or if the issue likely contributed to the outcome. In the former scenario, the issue is marked "Present", and in the latter scenario it is "Contributing." Some of the issues captured in the NFIMR database that relate to mothers' medical histories are shown in Figure 17. For comparison, when a similar issue was recorded in the Pregnancy Risk Assessment Monitoring System (PRAMS), the prevalence of that issue among all Delaware women with live births surveyed is also shown. The most recent year for which Delaware PRAMS data is available is 2009, and though this is earlier than the majority of FIMR cases, this was the closest group that could be used as a comparison to the FIMR cases. Forty-five percent of FIMR mothers had a history of a miscarriage or elective abortion that was deemed present by the CRTs, and in 2% of cases this history was deemed contributing to the fetal or infant death. The presence of such a history is much more prevalent in FIMR cases compared to the 2009 PRAMS cohort, of whom only 14% had a history of a miscarriage before 20 weeks.⁹ Among FIMR mothers, 6% had a history of a prior fetal loss, while among PRAMS respondents, only 1.5% had such a history in the 12 months prior to their last pregnancy. A pre-existing history of diabetes was also more prevalent among FIMR mothers than among PRAMS respondents. Six percent of FIMR mothers had history diabetes noted as present, and an additional 7% had a history of diabetes that contributed to their pregnancy outcome. In contrast, pre-existing diabetes was reported in 3% of PRAMS respondents. Prevalence of gestational diabetes,

prolonged rupture of membranes (PROM) and placental abruption did not differ much between FIMR mothers and PRAMS results.

Some additional factors in mothers' medical histories were also tracked using the internal FIMR database. Eight percent of mothers (n=6 out of 80) were noted to have had preconception care. Eleven mothers received antenatal steroids out of 19 mothers who had infants born between 23 and 36 weeks gestation, thus representing 58% of eligible mothers. In 2017, FIMR CRTs will start tracking the receipt of 17-progesterone by mothers who are at risk of early miscarriage.



Figure 17: Maternal medical issues in FIMR cases (present or contributory) and from the PRAMS 2009 analysis



Source: PRAMS survey available from <http://dhss.delaware.gov/dph/chca/files/prams2009finaloct2012.pdf>, accessed on June 26, 2017.

^PRAMS question: during the 12 months before you got pregnant, did you have a miscarriage, fetal death or stillbirth before 20 weeks gestation

*PRAMS question: during the 12 months before you got pregnant, did you have a miscarriage, fetal death or stillbirth after 20 weeks gestation

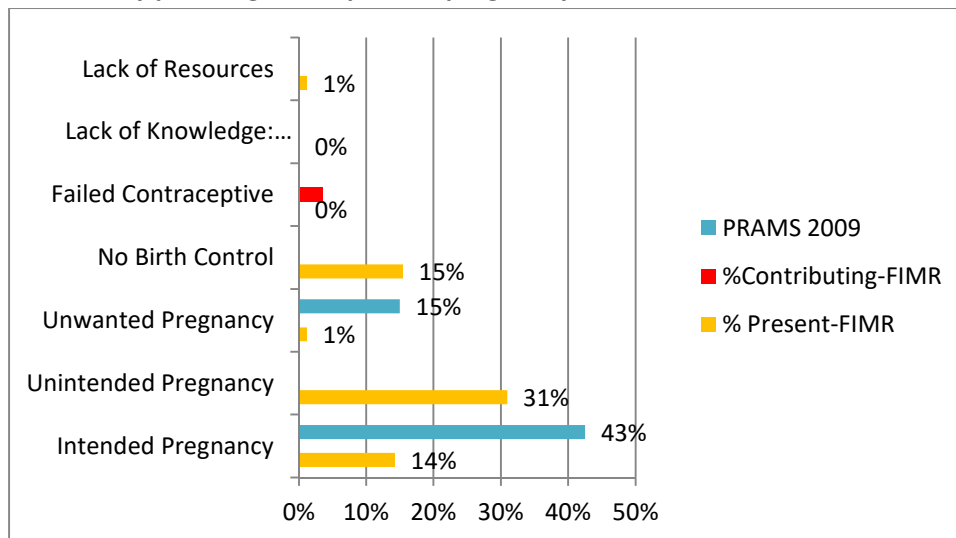
PROM=prolonged rupture of membranes, PPROM=premature prolonged rupture of membranes, TAB=therapeutic abortion

Family planning

The use of family planning services are captured in FIMR cases to attempt to understand mothers’ attitudes and knowledge prior to their pregnancy as well as in the postpartum period. Figure 18 shows some of the CRT determinations of family planning issues prior to the index pregnancy in FIMR cases as compared to attitudes of respondents in the 2009 PRAMS survey. Without a maternal interview, intent of pregnancy is not often known: in 14% of FIMR cases the CRTs determined that the mother did intend to get pregnant, while in about one-third of cases (32%) the mother did not intend or did not want to be

pregnant. This is compared to 43% of PRAMS mothers who reported that they wanted to be pregnant and 15% who did not want to be pregnant.¹⁰

Figure 18: Family planning issues prior to pregnancy, FIMR cases and 2009 PRAMS analysis



Source: PRAMS survey available from <http://dhss.delaware.gov/dph/chca/files/prams2009finaloct2012.pdf>, accessed on June 26, 2017.

In the postpartum period, a lack of documented family planning counseling was a FIMR finding in 43 cases (51%) and thus the most frequently noted finding. Four women (5%) accepted long acting reversible contraception (LARC) in the postpartum period.

Education

Seventy-one percent of FIMR mothers (n=57) returned for their postpartum visit. FIMR CRTs tracked the receipt of documented birth spacing education in the postpartum period, either right after delivery or at the postpartum visit. Twenty-nine percent of mothers (n=24) received birth spacing counseling, however only 4% (n=3) were counseled to wait at least 18 months before getting pregnant again as per the American Congress of Obstetricians and Gynecologists (ACOG) recommendations. Sixty mothers (71%) did not have documented birth spacing education.

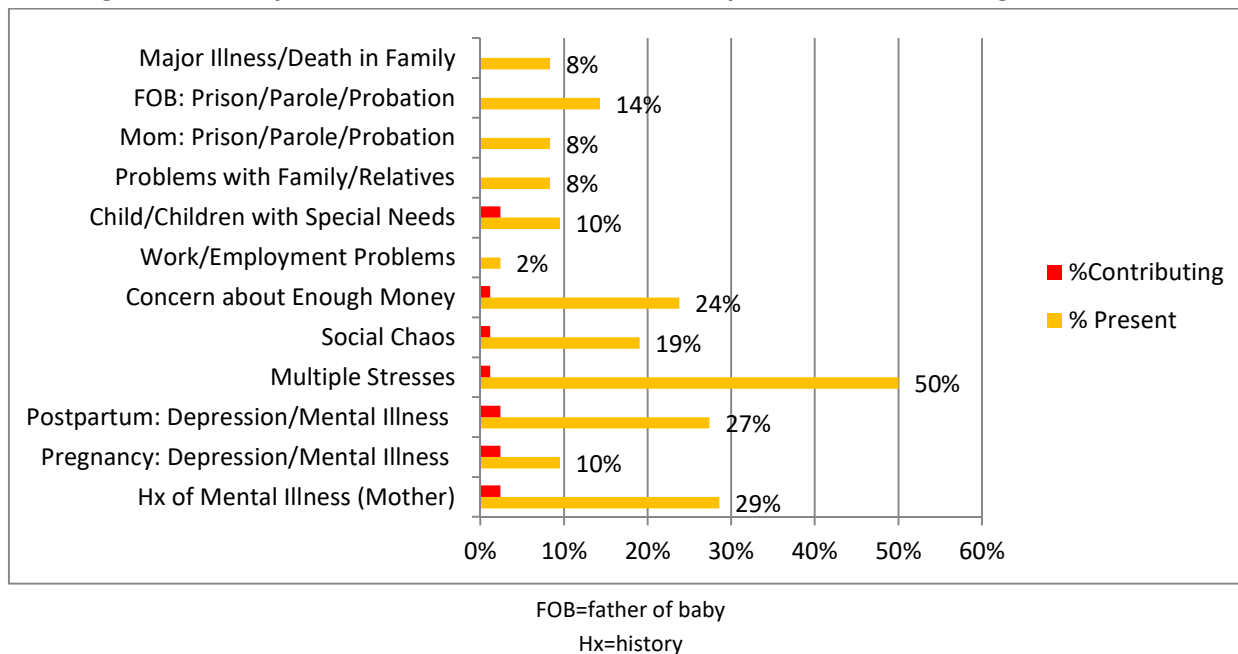
Fetal kick counts education was documented in 45% of FIMR cases (n=38) at any point in the prenatal period. For 2017 FIMR CRTs will continue to track receipt of fetal kick counts education but will only record this education as relevant if the mother made it beyond 24 weeks in her pregnancy as that is the recommended time to give this education.

Social Determinants of Health: Pertinent FIMR Findings

For several years FIMR CRTs have been tracking psychosocial factors in mothers’ lives that may have caused stress and had detrimental effects on their health. These factors are best assessed through the maternal interview, which was available in 34% of cases in 2016. The NFIMR database captures some

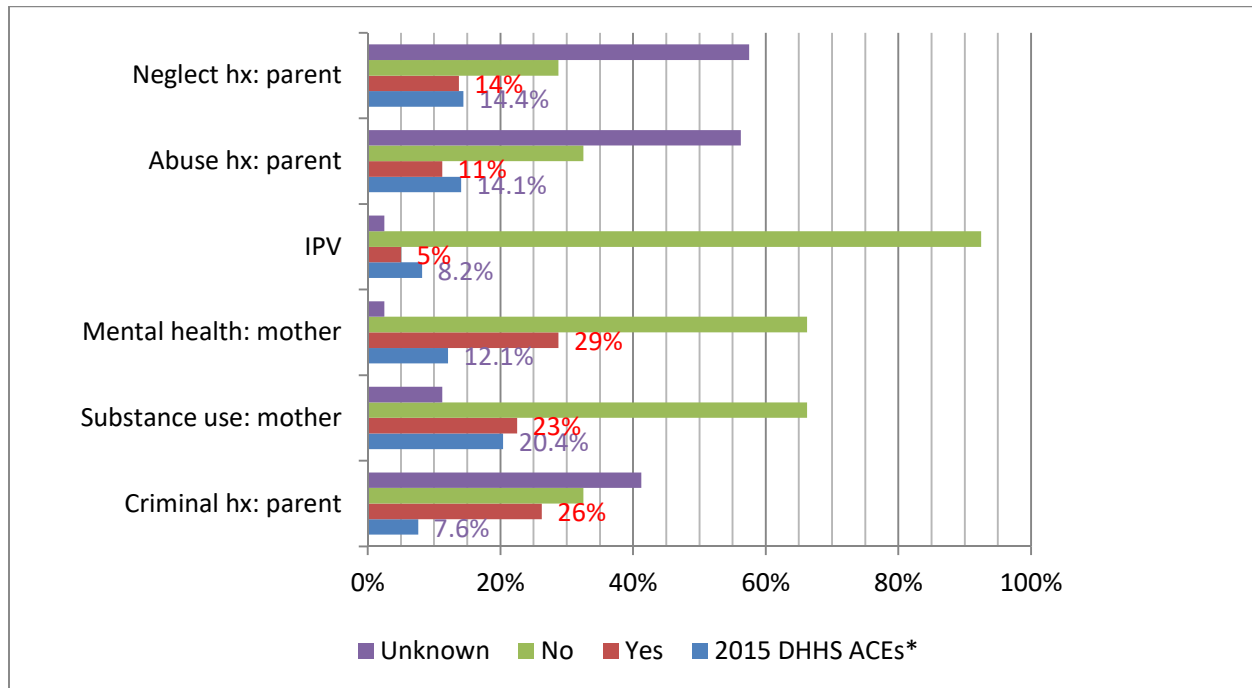
data on family transitions and mental health and stress. These factors identified as present or contributing in FIMR cases is shown in Figure 19. In 50% of FIMR cases, mothers had multiple stresses, 29% had a history of mental illness, and 27% had depression or mental illness in the postpartum period. In 52% of cases (n=44) there was documentation of depression screening; 68% of cases (n=57) had documented intimate partner violence (IPV) screening.

Figure 19: Family transition and mental health issues present or contributing in FIMR cases



FIMR staff also tracked the presence of other social determinants of health in the mothers' and fathers' (when available) histories (Figure 20). Two of these factors, the presence of a history of neglect or abuse in childhood, correspond to ACEs. History of abuse or neglect was not known in a little over 50% of FIMR cases, and criminal history was unknown in 41% of cases. History of neglect or abuse was present in 14% and 11% of cases, respectively, which is comparable to the prevalence reported in the Delaware ACEs study.¹¹ Criminal history—either for the mother or father—was present in 26% of FIMR cases. Two FIMR cases were active with DFS at the time of death, and in 13 cases there was a DFS history with the family. Moving forward, FIMR staff will distinguish between mothers' and fathers' histories and the presence of these ACEs and psychosocial risk factors as they are recorded in the tracking database.

Figure 20: Psychosocial factors and adverse childhood experiences among FIMR cases

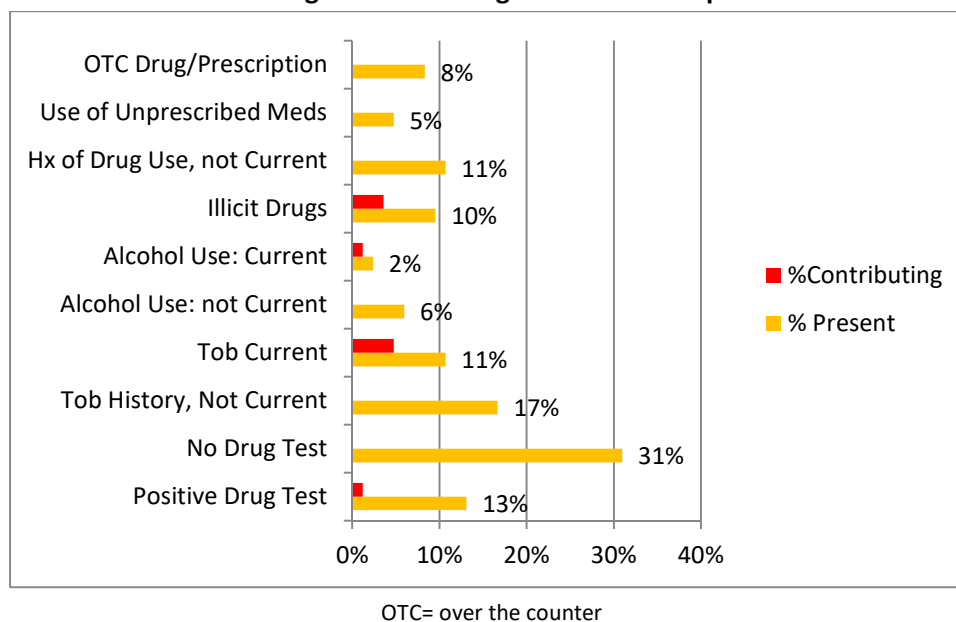


* Torrance CA, Williams K, Brown E, Olson K, Miller A, Newman L, Papas MA. Adverse childhood experiences negatively impact health behaviors and chronic disease risk among adults residing in Delaware. Delaware J Public Health 2016, 2(5): 68.

Substance Abuse: Pertinent FIMR Findings

Among FIMR cases, 39% of mothers (n=33) were not screened for drug use. Two-thirds of cases occurred in 2014 or earlier, so less drug testing may have been done then as compared to more recent years when the opioid epidemic has been a growing public health concern. Figure 21 shows present and contributing issues that were identified in FIMR cases. Of the 60% of mothers (n=50) screened for drug use, 26% of them tested positive, most commonly for marijuana. Methadone, Percocet, benzodiazepine and cocaine use made up a small percent of drug positive cases. FIMR CRTs and staff support revisions to the NFIMR database to capture more detailed information on substance use history and screening in the future.

Figure 21: Present and contributing factors relating to substance exposure and abuse in FIMR cases



Home Visiting: Pertinent FIMR Findings

Low rates of referrals to evidence-based home visiting services continue to be a prominent finding in FIMR case reviews. For the 2016 cases, which date from 2010 to 2016, only 8% (n=7) were referred to evidence-based home visiting or hospice programs, and in two cases the mother or infant was enrolled. Seventy-seven cases (92%) were not referred to any such home-based program. This lack of referral and underutilization of home visiting services is a recurrent finding. In the future, FIMR staff will track the setting for prenatal care to see if referral rates differ among public/clinic-based patients and private patients. There may also be confounding based on having older cases in the FIMR cohort, as it is in recent years that there has been more emphasis on increasing awareness and referrals to evidence-based home visiting services.

Trainings, Conferences and Professional Development

In May 2016, the Chair of the Commission (Dr. Garrett Colmorgen), the MMR Coordinator (Joan Kelley, RN), the Executive Director (Anne Pedrick), and Dr. Meena Ramakrishnan had the opportunity to attend the 2016 ACOG-CDC Maternal Safety and Mortality Meeting “ Optimizing Measurement and Mobilizing for Action” in Washington, D.C. It was a great opportunity to learn about new prevention initiatives on the following topics: severe maternal morbidity, obesity, maternal safety update, maternal mental health, state maternal mortality reviews, and maternal mortality measurement.

As part of the SDY grant, representatives from Delaware are required to attend the reverse site visit yearly at the CDC in Atlanta. This year the meeting occurred in October 2016. Those individuals representing Delaware included: Marjorie Hershberger (SDY Panel Chair), Anne Pedrick (CDRC Executive

Director), Julia Vekasy (Division of Forensic Sciences Investigator), and Dr. Lyndsey Emery (Assistant Medical Examiner). The Delaware team submitted a poster presentation on the Girl Scout Infant Safe Sleeping Project that was completed in 2016 (Figure 22).

Figure 22: Girl Scout safe sleep art project poster, exhibited at the CDC, Atlanta, GA, October 2016

Girl Scout Safe Sleep Art Project in the State of Delaware
Marjorie L. Hershberger, MS, RN-BC, PNP-BC, CPNP, Anne Pedrick, MS
Delaware Child Death Review Commission

Issue Statement:
To reach out to communities and young girls with a creative program that would promote, educate, and support the Safe to Sleep message.


Results:
Fourteen girl scouts from two troops participated. The pre and post quizzes had a total of 98 possible correct answers. The pre-quiz demonstrated a 75% correct response rate. The post-quiz demonstrated a 95% correct rate, showing a 20% improvement after education.


Background:
The National Institute of Child Health and Human Development (NICHD) launched the Back to Sleep Campaign 22 years ago. The purpose was to raise awareness and prevent Sudden Infant Death Syndrome (SIDS). Since that time, professionals and advocates have tried numerous methods to raise public awareness through the use of products. Gerber and Johnson & Johnson were strong marketers of the "Back to Sleep" message. In 2011, NICHD updated the Back to Sleep message to the Safe to Sleep Campaign which included the entire sleep environment. However, finding creative ways to keep the message in the public awareness continues to be a challenge.


Conclusion:
This small project demonstrated that developing creative programs, such as this art poster contest can be successful in not only educating young girls about Infant Safe Sleep, but enabling their knowledge and creativity to penetrate the community by keeping the infant safe sleep message in the public awareness.


Methods:
An art poster contest was developed through a small grant from the National Cribs for Kids® and introduced to two Delaware Girl Scout Troops. A pre-quiz was administered, followed by an educational presentation on the American Academy of Pediatric (AAP) recommendations for a safe infant sleep environment. Participants were encouraged to submit original art work that presented the safe to sleep message utilizing the AAP recommendations. After four weeks, a post-quiz was given and the pre and post quiz results were compared. The winning poster and runner up were selected by members of The Infant Safe Sleep Community Action Team. The winning poster art work was placed on a tote bag which contained an infant sleep sac, Sleep Baby Safe and Snugg book, and Safe Sleep literature. These were distributed to high risk populations throughout the State of Delaware.


Case Registry Implications:
This small project shows potential to be utilized through-out the country by making it a nationwide Girl Scout badge, with the potential to reach thousands of young girls and their communities.












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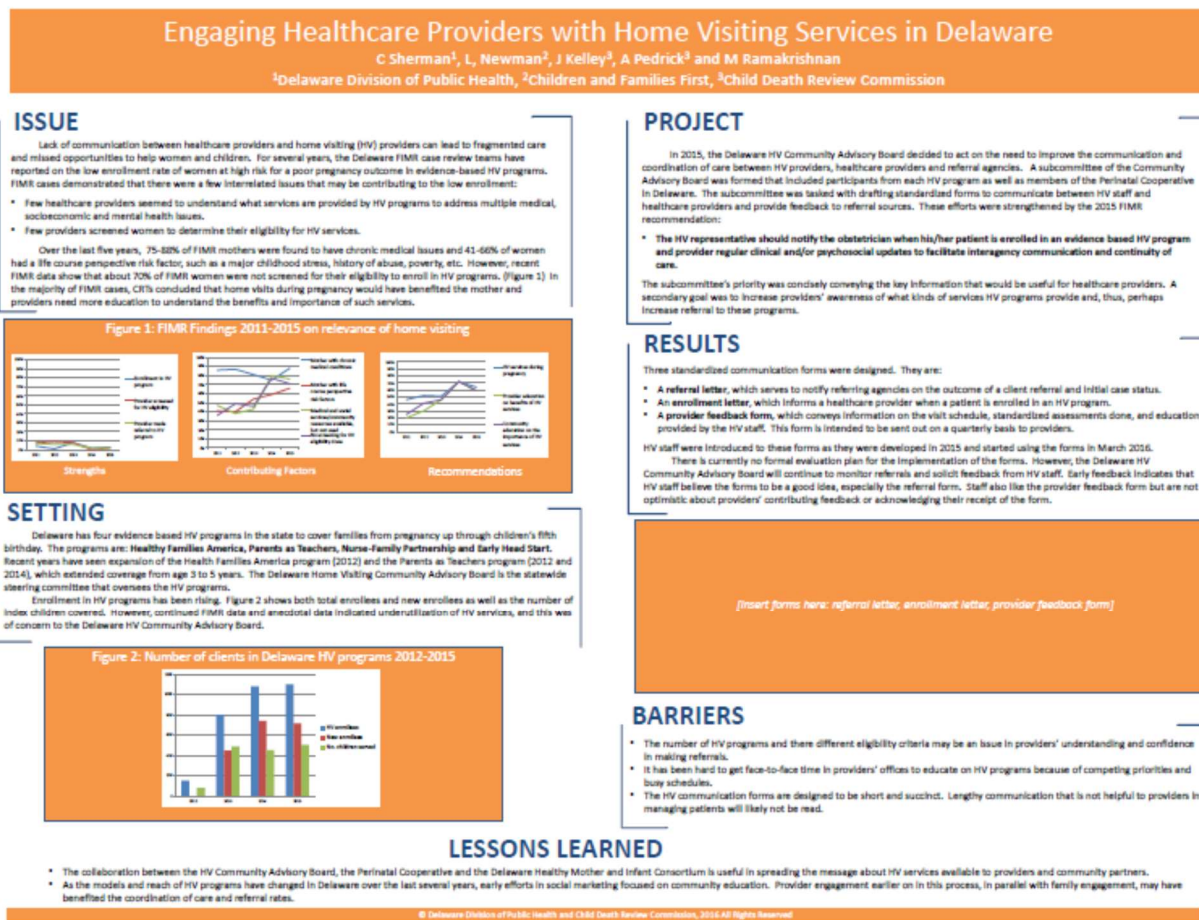
National Center for Chronic Disease Prevention and Health Promotion
Maternal and Infant Health Branch, Division of Reproductive Health



www.cdc.gov | Contact CDC at 1-800-CDC-INFO or www.cdc.gov/info
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

In September 2016, the FIMR Coordinator (Joan Kelley, RN) and Dr. Meena Ramakrishnan attended the Maternal Child Health Epidemiology Conference in Philadelphia, PA. The Delaware team exhibited a poster entitled, “Engaging healthcare providers with home visiting services in Delaware” (Figure 23). At the invitation of AMCHP (Association of Maternal Child Health Programs), Delaware also participated in an MMR mock case review as part of the capacity building efforts to standardize MMR processes and data collection nationwide.

Figure 23: “Engaging healthcare providers with home visiting services in Delaware,” poster exhibited at the Maternal Child Health Epidemiology Conference, Philadelphia, PA, September 2016



In October 2016, Dr. Meena Ramakrishnan attended a CDC training on the MMR database system (MMRDS) in New Brunswick, NJ.

In addition, a formal CDRC Commissioner orientation was conducted in the spring of 2016. A commissioner handbook will be released in 2017. All materials will be posted on the CDRC website when finalized.

Maternal Mortality Review

Overview: 2016

In 2016, CDRC staff continued to use the CDC-developed MMR database system (MMRDS) while providing input for the creation of a new CDC database, the Maternal Mortality Review Information Application (MMRIA). Delaware was one of four states contributing aggregate data to the CDC document, “[Report from Maternal Mortality Review Committees: a View into their Critical Role](#)” which is available at: <https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAREport.pdf>.

The Delaware MMR program reviewed six cases in 2016: four in the MMR panel meeting and two through internal staff review. The two cases that were internally reviewed were several years old and still pending prosecution, and for that reason they could not be brought for full panel review. Two of the six MMR cases were determined to be pregnancy-related, two were pregnancy-associated but not pregnancy-related, and in two cases the pregnancy-relatedness could not be determined. A pregnancy-related death is defined as a death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy. A pregnancy-associated but not related death is defined as a death that occurs during pregnancy or within one year of the end of pregnancy due to a cause unrelated to the pregnancy. Two of the six cases were deemed preventable.

MMR Findings: 2016 Cases

MMR findings relate to several categories of critical factors, which are defined by the CDC as:

1. Patient/family
2. Community
3. Provider
4. Facility
5. System

In 2016 cases general findings by critical factor and issue included:

- Provider education on screening for Interpersonal Violence (IPV) as per the ACOG recommendations and education on the services and support offered by the 24-hour domestic violence hotline
- Facility policies & procedures for the routine use of drug screens
- System referral and decision making algorithms for notification of the medical examiner in cases of maternal death

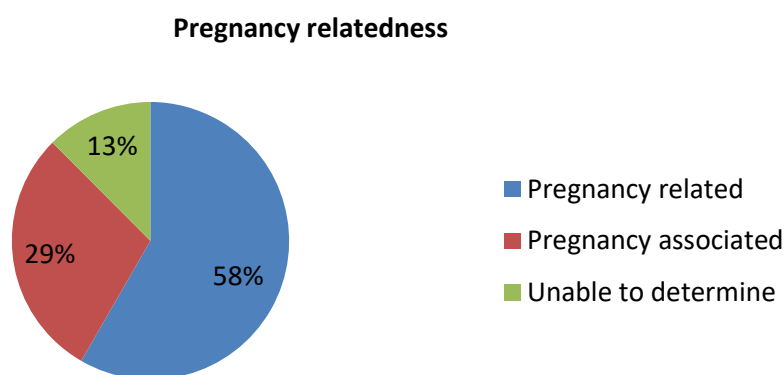
Multiyear Summary: MMR 2011-2016

With the inclusion of 2016 cases, the Delaware MMR program has reviewed 24 cases in total since its start of reviews in 2011. The key characteristics and findings from these 24 cases are compiled here for more quantitative review. The 24 maternal deaths reviewed span the years of 2009 to 2015. Equal proportions (42%) of White and Black women are represented. Three of the 24 cases involved a family interview. In 25% of cases (n=6), a substance abuse issues was identified, and in 29% (n=7) a mental health issue was identified. Three cases involved confirmed or suspected IPV. ACEs were largely unknown for the MMR cases over these six years.

Delaware MMR uses the pregnancy checkbox on the death certificate to identify cases for MMR. Review of the method of case identification among the 24 MMR cases since the program's inception revealed that 17 cases, about 70%, were identified based on the pregnancy checkbox. Two cases were marked as "not pregnant" on the death certificate checkbox and hence were false negatives. Four cases were identified by CDRC staff through routine obituary searches. One case was also a FIMR case, and one case was reported by a provider to the CDRC staff. The lack of sensitivity and specificity of the death certificate's pregnancy checkbox is an issue in Delaware as well as other locales. Per the CDC report on MMR committees, the pregnancy checkbox is inaccurately marked as a false positive in 15% of cases and a false negative in 10-25% of cases. These findings nationally and in Delaware have prompted the CDRC staff to pursue establishing a formal process with the Division of Public Health's Office of Vital Statistics to routinely obtain linked birth and death certificate data as another method—in addition to the pregnancy checkbox—to identify potential maternal death cases.

Of the 24 MMR cases reviewed over six years, 58% (n=14) were determined to be pregnancy-related (Figure 24). Seven cases (29%) were pregnancy-associated but not pregnancy-related, and in three cases (13%) pregnancy-relatedness could not be determined.

Figure 24: Determination of pregnancy-relatedness in MMR cases (n=24)



One-third of pregnancy-related deaths occurred while the woman was still pregnant. Two-thirds of the deaths occurred within 42 days of the end of pregnancy (Figure 25). None of the pregnancy-related

deaths occurred between 43 and 365 days of the end of pregnancy. A higher proportion of pregnancy-related cases were determined to be preventable (57%) compared to non-pregnancy-related cases (Figure 26).

Figure 25: Timing of death in MMR cases: all cases compared to the subset of pregnancy-related cases

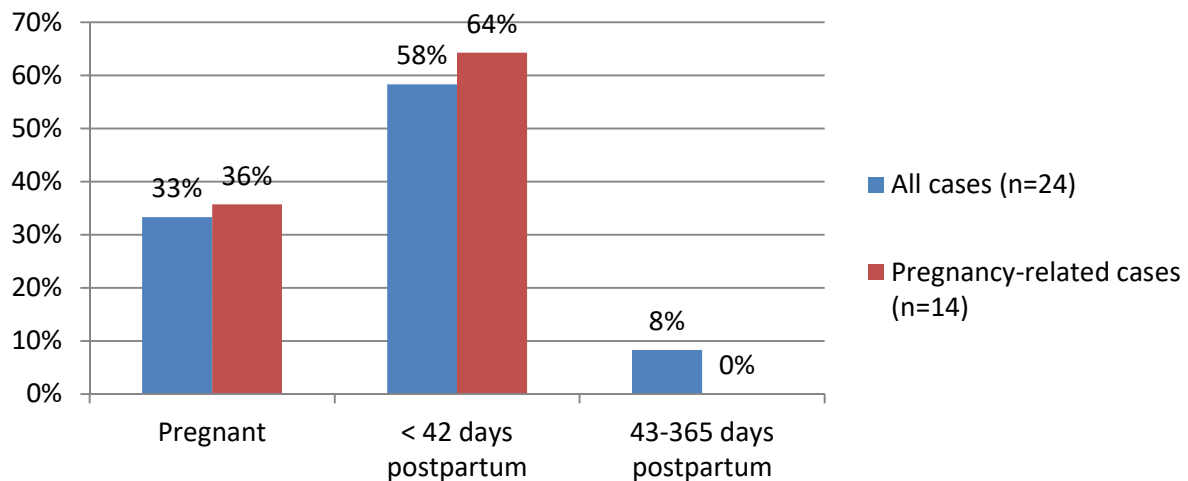
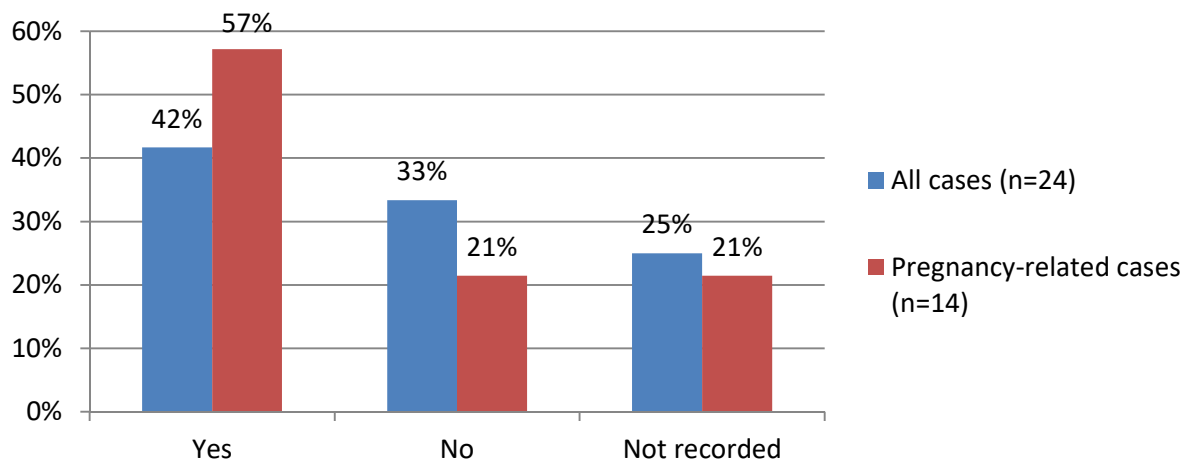


Figure 26: Preventability of MMR cases as determined by the MMR panel: all cases compared to the subset of pregnancy-related cases



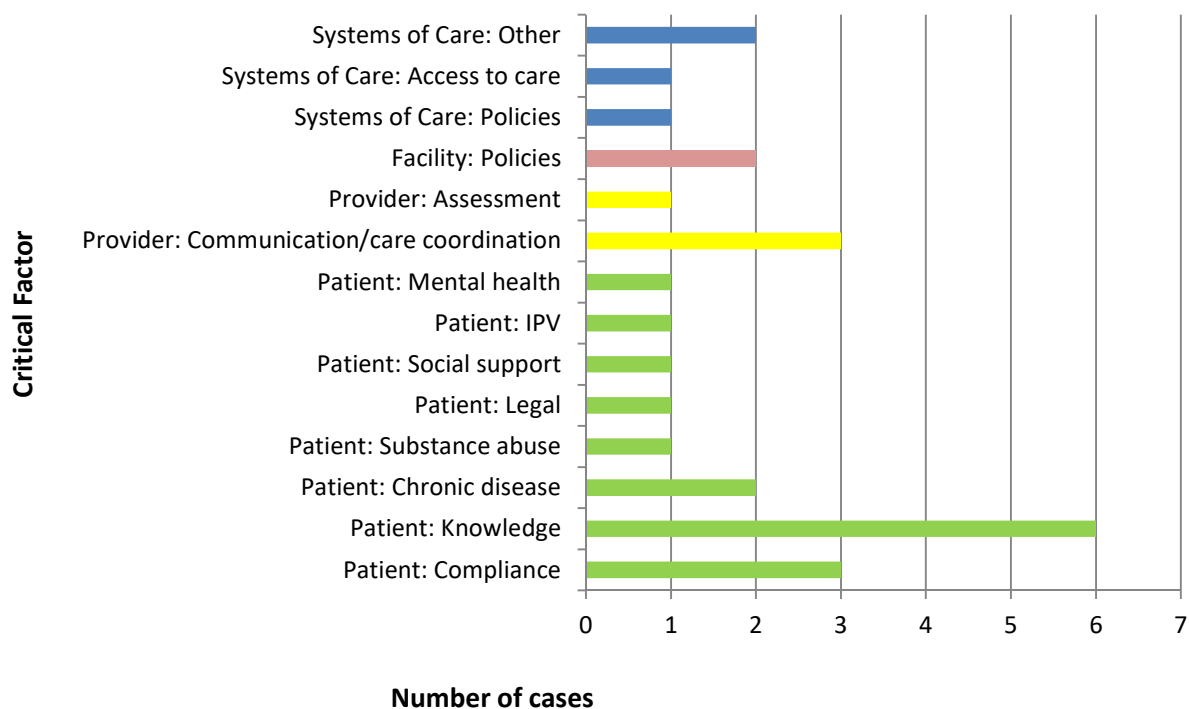
MMR Findings in Pregnancy-related Cases: Multiyear Review 2011-2016

Among the 14 pregnancy-related deaths, four (29%) were attributable to cardiovascular and coronary conditions, and two (14%) were caused by pulmonary conditions. The remaining eight deaths were

caused by cardiomyopathy, infection, embolism, accidental poisoning, blunt force injury, anesthesia complications, lupus nephritis, and complications of diabetes mellitus.

Critical factors identified in pregnancy-related deaths are summarized in Figure 26. The most common type of factor was at the patient level. Patient knowledge was identified as an issue in six cases, patient compliance in three cases, and patient chronic disease in two cases. Patient legal issue, patient social support, patient IPV and patient mental health were each identified in one case. In four cases, provider factors were identified: communication/lack of care coordination (n=3 cases) and provider assessment (n=1 case). In two cases facility policies and procedures were a critical factor; and in four cases systems of care was a critical factor: access to care (n=1 case), policies and procedures (n=1 case) and other system issues (n=2 cases).

Figure 26: Critical factors identified in pregnancy-related deaths, 2011-2016 MMR reviews (n=14)



Source: A Koch, personal communication. June 23, 2017.

Conclusion

Progress was made in 2016 in all three CDRC review programs to clear the backlog of older cases with the goal of doing more concurrent reviews in 2017. More specific data collection via the internal tracking tool will be an ongoing effort of staff and consultants, collecting relevant data and differentiating factors—such as maternal and paternal psychosocial history—when possible. CDRC staff will also continue to work with the CDC, AMCHP and the National Center for Fatality Review and Prevention (NCFRP) to optimally implement national standards for data collection and reporting.

Recurring themes across all reviews underscore the importance of the three key findings pertaining to the social determinants of health, the impact of substance abuse and addiction, and the underutilization of evidence-based home visiting services among high-risk groups. The CDRC continues to support efforts to address these important issues and implement better systems of care to serve women and children in Delaware.



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