2021 Annual Report

Child Death Review Commission







STATE OF DELAWARE Child Death Review Commission

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The Honorable John Carney, Governor State of Delaware

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Garrett H. C. Colmorgen, M.D., Chair

Working Together to Understand Why Children Die 7 Taking Action to Prevent Deaths

Mission Statement

The Child Death Review Commission was established "in order to provide its findings or recommendations to alleviate those practices or conditions which impact the mortality of children and pregnant women."

--Child Death Review Commission, Statute 31 Del. C. § 320



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Program Highlights

The Child Death Review Commission (CDRC) conducts three types of fatality review programs with a focus on maternal-child health: Child Death Review and Sudden Death in the Young (CDR/SDY), Fetal and Infant Mortality Review (FIMR), and Maternal Mortality Review (MMR). CDRC staff oversee subcommittees and collaborate with partners to implement recommendations based on these multi-disciplinary fatality reviews.

CDRC accomplishments and highlights in 2021 include:

- Retrospectively reviewed 48 CDR/SDY cases, 60 FIMR cases—of which eight included a maternal interview—and 11 MMR cases with five family interviews obtained.
- Transformed the Infant Safe Sleeping Community Action Team into the Delaware Safe Baby Committee, expanding its focus to include infant safe sleep practices, substance use ingestion, and abusive head trauma. The participants draw from multiple disciplines and represent community prevention members.
- Partnered with the Delaware American Academy of Pediatrics (AAP) to contribute monthly submissions to their provider newsletters. Received a grant from the National AAP and the National Center for Fatality Review and Prevention (NCFRP) to produce a webinar training series educating pediatricians on child fatality review. This will take occur in Fall 2022.
- Presented infant mortality information and FIMR findings at the <u>Infant Mortality Snapshot</u> webinar on January 19, 2021, hosted by KIDS Count in Delaware.
- Partnered with the Delaware Perinatal Quality Collaborative (DPQC) and the Delaware Section
 of the American College of Obstetricians and Gynecologists (ACOG) to provide "Strategies for
 Successful Care for Pregnant and Postpartum Women of Color" by Dr. Joia Adele Crear-Perry,
 MD, as part of the Delaware Maternal Health Awareness Day on 1/23/21. In addition, Dr. CrearPerry's talk was made available as part of a Lunch n' Learn series entitled "Addressing Racial
 Disparities in Women's Health" and conducted at various medical offices throughout the state.
- Conducted a joint retreat on February 16, 2021, with 30 participants from FIMR and MMR to develop a two-year action plan.
- Completed the work of the CDRC Home Visiting Committee with the release of a final report on March 14, 2022. The report is included in the 2021 annual report to offer timely recommendations for systemic change to assist Delaware's families.
- Conducted an SDY refresher training on May 5, 2021, for the Division of Forensic Sciences-Medical Examiner staff. The training provided an overview of the SDY program and consent procedure.
- Approved the dissolution of the Joint Committee on Substance Exposed Infants/Medically Fragile Children¹ on May 14, 2021. The Joint Committee successfully completed its goals and implemented the Medical Plan of Safe Care in Delaware's birthing hospitals for those birthing persons who do not require child welfare involvement.
- Provided Infant Safe Sleeping/Cribs for Kids training at a hospital emergency room, medical clinic, the Delaware Coalition for Injury Prevention, and a virtual program training for new agency distributors.

¹ FY21 CPAC Annual Report (visme.co)

- Significantly improved CDR/SDY data quality from 2014 to 2019, along with two other states, as mentioned in a national report. Delaware improved in timeliness and met national benchmarks. The report is titled <u>Monitoring Data Quality in the National Fatality Review-Case Reporting</u> <u>System: The First Five Years.</u>
- Collaborated with the DPQC, the Delaware Chapter of ACOG, and the Delaware Healthy Mother and Infant Consortium (DHMIC) to begin work on an educational video series that will highlight lessons learned from FIMR/MMR on effective communication between patients and providers. There will be four modules for this on-demand training, and Continuing Medical Education (CME) credits will be offered. The target audience will be medical professionals, nurses, and office managers. The education will apply a trauma-informed lens to help viewers recognize their individual biases and approach birthing persons and families with humility and a listening ear. The educational webinars are expected to be completed by 2023.
- Received technical assistance training from the NCFRP to participate in a learning cohort with five other states on the FIMR Storytelling Project. This important work began in November 2021 and will continue in 2022.
- Granted a small stipend from the Delaware Chapter of the American Trauma Society to develop an infographic on substance ingestion based on findings from deaths and near-deaths of children in the last five years. This analysis will be conducted jointly with the Office of the Child Advocate (OCA). The infographic is expected to be released in July 2022 and a public awareness campaign.
- Continued our commitment to increasing transparency, identifying and addressing structural racism and discrimination, partnering for health equity in the fatality reviews, and listening to the voices of community members who have had a loss.

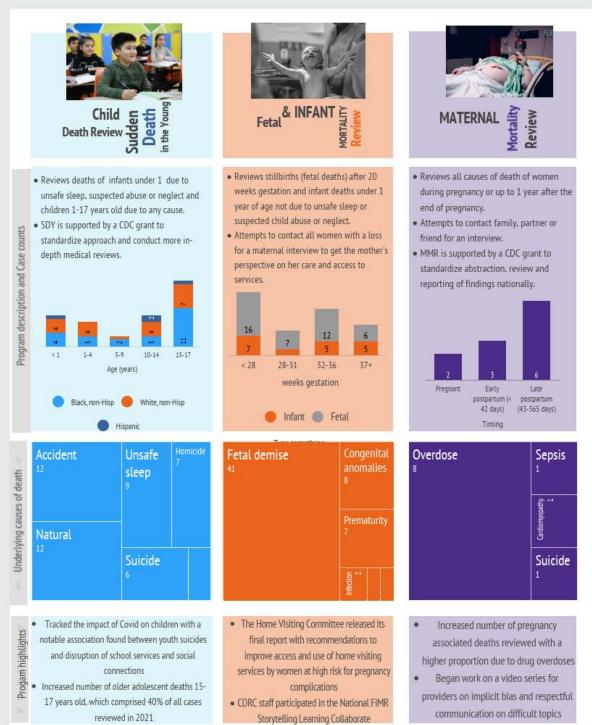
The key characteristics of cases from each fatality review program are described separately in the following pages. Findings and recommendations are put forth based on these case reviews.



Child Death Review Commission

Oversees three fatality review programs, each consisting of multidisciplinary teams that delve into the facts surrounding each case, the programs and systems of care with which the child, mother or family interacted and opportunities for improvement. Ultimately the CDRC seeks to eliminate all preventable deaths in childhood and among women during and after pregnancy. *Every child and mother deserves a tomorrow.*





Child Death Review / Sudden Death in the Young

The Child Death Review (CDR) and Sudden Death in the Young (SDY) panels review sudden and unexpected deaths in children and youth under 18. Among infant deaths, CDR and SDY specifically focus on any deaths that may involve abuse, neglect, or an unsafe sleep environment. Since 2014 the CDRC has received grant support from the National Institutes of Health and the Centers for Disease Control and Prevention (CDC) to conduct the SDY program in keeping with the highest national standards. Delaware's data entered into the SDY case registry helps researchers investigate the causes and associated risk factors for sudden and unexpected child deaths.

In 2021, 48 cases were reviewed: 33 by CDR and 15 by SDY panels. These include nine infant deaths and nine unsafe sleep deaths. Four cases were jointly reviewed with the Child Abuse and Neglect (CAN) panel under the direction of the Office of the Child Advocate. CDR/SDY cases were equally split between males (50%, n=24) and females (50%, n=24). Race and ethnicity varied by age group, especially among older adolescents 15-17 years old, where Black youth outnumber all other groups (Figure C1). There was a jump in the number of 15–17-year-old cases reviewed in 2021: this age group made up 40% of CDR/SDY cases in 2021, twice as high as the average proportion of cases seen in the four prior years of review. (For more details, see the CDRC 2021 data addendum.) Homicides, accidents, and suicides were the leading causes of death in this older adolescent age group (Figure C2).

In Delaware overall, the five-year average mortality rate for 1–19-year-old children has plateaued over the last ten years. The most recent rate reported is 26.5 deaths per 100,000 children 1-19 years old for 2015-2019.² However, a deeper dive into the causes of death revealed that the rate of deaths from unintentional injuries had decreased steadily while homicide deaths have increased significantly (Figure C3). In Delaware, many youth homicides involve guns; in 2021, six child deaths reviewed involved a firearm, including five homicides and one suicide death. All firearm victims were Black youth. The racial disparity in gun death is well documented nationally, especially among homicide victims, with young Black males (15-34 years of age) being 20 times more likely to die of gun-related homicide than White males.³



Gun Violence

Firearms were the leading cause of death in 2019 for American children and teens ages 1-19, prematurely taking the lives of nearly 3,400 Americans . . . and accounting for nearly one in ten deaths in this age group. Of these youngest victims, 44% were Black. More than half of all Black teens (15-19) who died in 2019 -- a staggering 57% -- were killed by gun violence. While suicides are 60% of all gun deaths across the whole U.S. population, homicides are the most common type of gun death among children and teens -- 60% of child and teen gun deaths were homicides and 34% were suicides.³

² Delaware Health Statistics Center. <u>Delaware Vital Statistics Annual Report</u>, 2019. Delaware Dept of Health and Social Services, Division of Public Health, 2021.

³ Educational Fund to Stop Gun Violence and Coalition to Stop Gun Violence. (2021). <u>A Public Health Crisis Decades</u> in the Making: A Review of 2019 CDC Gun Mortality Data.

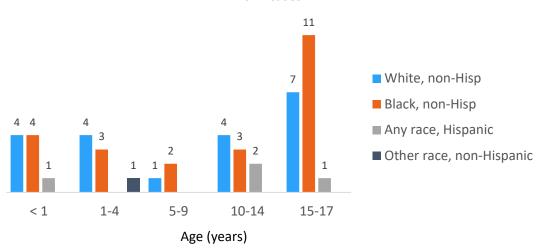
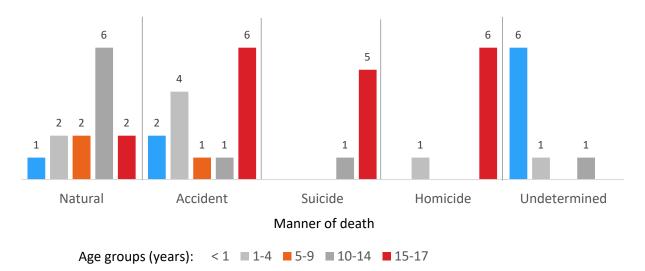


Figure C1: Age groups by Race/Ethnicity represented in the CDR/SDY 2021 cases

Figure C2: Number of cases by age and manner of death



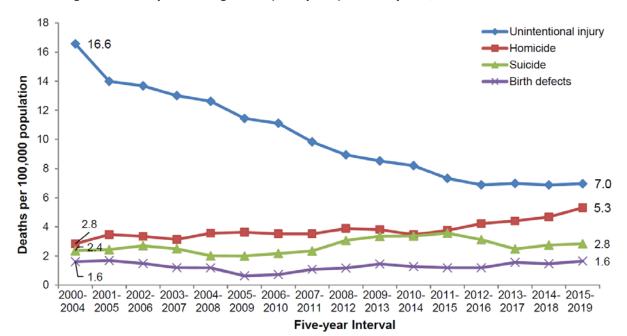


Figure C3: Five-year average child (1-19 years) mortality rate, Delaware 2000-2019

Source: Delaware Department of Health and Social Services, Division of Public Health, Delaware Health Statistics Center

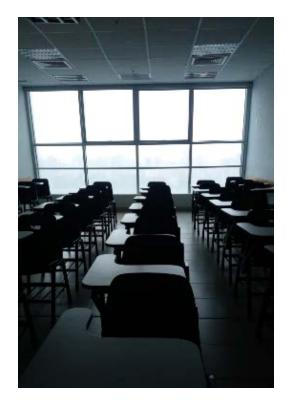


Impact of Covid

Twenty-nine CDR/SDY deaths (60%) reviewed occurred after the onset of the COVID-19 pandemic. Of these, 20 deaths occurred during the Covid stay-at-home order period March-June 2020. Two natural deaths were directly due to Covid, and both children had chronic medical conditions. Nine deaths were indirectly linked to Covid, including all six suicides, two accidental deaths, and one homicide death. In 15 deaths--52% of post-Covid cases--children experienced significant disruptions in school services. This data from Delaware reviews correspond to national trends that have recently been published on the deterioration in youth mental health attributed to Covid and the pandemic response (Figure C4). Covid has resulted in an exacerbation of the worsening trends in youth mental health and well-being. A recent article on the 2021 Adolescent Behaviors and Experiences Survey states that over half of youth had experienced emotional abuse in the home, and 1 in 10 had experienced physical abuse since the onset of the pandemic.⁴ Feelings of sadness and hopelessness had been reported by 1 in 3 high school students before the pandemic but now are reported by almost half of students (44%).⁵

COVID-19 Updates

Covid's impact on disruption of school and supports for children are evident in **all six youth suicides**, two accidental deaths and one homicide. The mental and emotional well-being of children in the midst of the pandemic and its response needs to remain a public health priority.



⁴ Krause KH, et al. <u>Disruptions to School and Home Life among High School Students during the COVID-19</u>

Pandemic—Adolescent Behaviors and Experiences Survey, United States, January-June 2021. MMWR Suppl 2022; 71(3).

⁵ Jones SE, et al. <u>Mental Health, Suicidality, and Connectedness among High School Students during the COVID-19</u> <u>Pandemic—Adolescent Behaviors and Experiences Survey</u>, United States, January-June 2021. *MMWR Suppl* 2022; 71(3).

CHILD DEATH REVIEW / SUDDEN DEATH IN THE YOUNG

Figure C4 Youth Mental Health:

The impact of Covid exacerbated a concerning trend

Even before the Covid pandemic, rates of youth suicide contemplation, suicide attempts and peristent feelings of sadness or hopelessness were rising among US high school students. Source: CDC, Youth Risk Behavioral Survey: Data summary and trends report, 2009-2019.

> Covid worsened the traumatic stressors for many adolescents. A recently published CDC survey found that in 2021:



Experienced emotional Reported poor abuse by a parent or mental health other adult in the home, during the COVIDincluding swearing at, 19 pandemic insulting or putting down the youth



Reported poor Reported feeling mental health persistently sad luring the COVID- or hopeless 19 pandemic during the past



Experienced physical abuse by a parent or other adult in the home, including hitting, kicking or beating

Source: CDC, Adolescent Behaviors and Experiences Survey, MMWR Surveillance Supplement 2022; 71(3).

Delaware data reflects these national trends.

✓ 100%

Of youth suicides showed signs of significant stress, disconnectedness and disruption due to Covid*

🔺 2x

Number of 15-17 years old deaths reviewed in 2021 compared to the prior two years of reivew

*Findings in CDR/SDY review note some at-risk youth had numerous absences from virtual schooling that were not addressed by the regular authorities during the pandemic

Youth connectedness is an important pro

🗧 factor

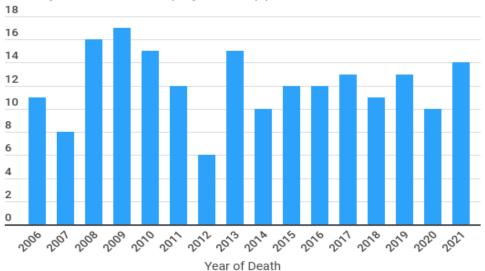
Connectedness refers to a sense of being cared for, supported and belonging in either a school, family or community setting.

Youth who feel connected at school or at home are 66% less likely to experience health risk behaviors related to mental health, sexual health, substance use and violence in adulthood.

RJ, et al. Adolescent Connectedness and Adult Outcomes. Pediatrics, 2019; 144(1).

Unsafe Sleep Deaths

In 2021, CDR/SDY panels reviewed nine cases of unsafe sleep-related deaths. All but one death occurred in infancy. In five cases, documented infant safe sleep education was in the medical record. One family was also a Cribs for Kids recipient. The number of unsafe sleep deaths has remained relatively constant over the last ten years, as shown in Figure C4. In all deaths, there are at least one and more often multiple environmental risk factors such as improper sleep surface, bedding or toys near the child, or co-sleeping (Table C1). The Delaware Pregnancy Risk and Assessment Survey (PRAMS) offers a comparison group by surveying women who have recently delivered in Delaware about their infant sleep practices. For more details, see the CDRC 2021 data addendum.



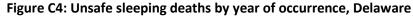


Table C1: Risk factors p	present in unsafe slee	p-related deaths con	npared to PRAMS
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		2021 (n=9)	2020 (n=10, infant only)	2019 (n=12)	PRAMS 2019 ¹
Ш	Not in crib, bassinette, side sleeper or baby box	78%	80%	100%	9%
٢	Not sleeping on back	44%	40%	50%	22%
Į.	Unsafe bedding or toys near infant	89%	70%	92%	9%
	Sleeping with other people	56%	40%	75%	24%
*	Intrauterine drug exposure	17%*	30%	42%	
	Tobacco use: mother	38%*	25%	67%	19%
	Adult was alcohol or drug impaired	11%	33%	67%	

¹DPH. Delaware Pregnancy Risk Assessment Monitoring System (PRAMS) 2019 Analysis. Available at: <u>https://www.dhss.delaware.gov/dhss/dph/hp/files/PRAMS2019.pdf</u>. Accessed February 11, 2022. *Only infant unsafe sleep deaths included

Review to Action Delaware Safe Baby Committee

As part of the CDRC-CPAC 2020 Joint Action Plan, the Infant Safe Sleeping Community Action Team was transformed into the Delaware Safe Baby Committee with a new mission statement and objectives:

- Improve the education provided on infant unsafe sleeping to focus on a comprehensive interdisciplinary approach that will ultimately decrease the number of unsafe sleep deaths. Goals include the following:
 - 1. Revitalize the Infant Safe Sleeping Program Community Action Team (TISSPCAT) by revisiting the name, objectives, and mission and by expanding its membership.
 - 2. Review current training and educational materials.
 - 3. Develop or improve prevention messaging to families.

This committee started in July 2021 and met four times before the end of the year. In addition to birthing hospital representatives, the following agencies also participate: the Division of Family Services (DFS), the Attorney General's office, and the OCA. Additional community members will be solicited in 2022.

As a result of this new community-focused committee, the following has occurred:

- An infant safe sleep social media campaign was developed and shared via community partners.
- The committee was educated on what prevention education is provided on unsafe sleeping deaths locally and nationally.
- A medical provider survey was developed and distributed.
- Work has begun on a substance use ingestion prevention campaign in partnership with the OCA.



The CPAC-CDRC Joint Action Plan

Findings from CDR/SDY reviews inform the Child Protection Accountability Commission (CPAC)-CDRC Joint Action Plan. The most recent plan was developed in September 2020 and is reviewed regularly by CPAC and CDRC staff. The joint <u>action plan</u> can be accessed on the CDRC website.





Fetal and Infant Mortality Review

FIMR was implemented in 2007 as one of the recommendations put forth by the Governor's Infant Mortality Task Force convened in 2004-2005 in response to Delaware's unacceptably high infant mortality rate (IMR). Along with the concurrent establishment of the Delaware Healthy Mother and Infant Consortium (DHMIC), FIMR has been an integral part of the continual surveillance and quality improvement efforts to address the factors underlying fetal and infant deaths. Since its recent peak of 9.3 infant deaths per 1,000 live births in 2000-2004, the Delaware five-year average IMR has decreased 23% to 7.2 deaths per 1,000 live births in 2015-2019, the latest period for which the Office Vital Statistics has reported the IMR.⁶ However, this progress has not been evenly achieved, as noted by a 3 to 1 Black: White IMR disparity ratio. The Delaware fetal death rate is also similarly three times higher among Black babies compared to White babies, with 9.8 Black fetal deaths per 1,000 live births compared to 3.4 White fetal deaths per 1,000 live births in 2019.⁷

This statewide racial disparity is reflected in the group of cases reviewed by FIMR teams in 2021. As shown in Figure F1, Black babies make up the majority of FIMR cases while representing only about 1 in 4 live births in the state. Sixty cases were reviewed by FIMR Case Review Teams (CRTs) in 2021, with two-thirds representing fetal deaths (n=41) and one-third representing infant deaths (n=19). This is a higher proportion of fetal deaths than in prior years, and a more detailed analysis reveals this was primarily due to a decrease in infant referrals to the CDRC since the onset of the Covid pandemic in mid-2020 and the resulting strain put on staff at the Division of Public Health (DPH). The FIMR cases reviewed in 2021 represent deaths occurring in the calendar years 2020 (n=49) and 2021 (n=11), with an average of eight months passing between the occurrence of a death and its review by a FIMR CRT.

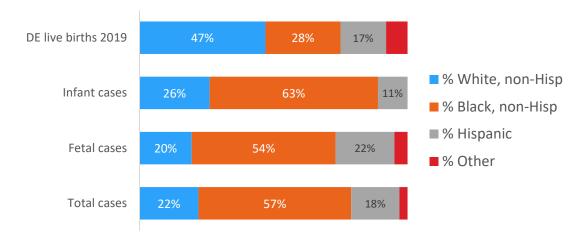


Figure F1: Race/ethnicity by case type

⁶Delaware Health Statistics Center. <u>Delaware Vital Statistics Annual Report, 2019</u>. Delaware Dept of Health and Social Services, Division of Public Health, 2021.

⁷ Delaware Health Statistics Center. <u>Delaware Vital Statistics Annual Report, 2019</u>. Delaware Dept of Health and Social Services, Division of Public Health, 2021.



Underlying Causes of Death

The underlying cause of death in infant cases and contributing factors identified in fetal cases, as determined by the CRTs, are shown in Figure F2. In fetal deaths, the contributing factors most often relate to maternal complications of pregnancy, with placental abruption (29%, 12 out of 41 cases), chorioamnionitis (22%, 9 out of 41 cases), and preeclampsia (15%, 6 out of 41 cases) comprising the top three factors. Among infant cases, congenital anomalies (42%) slightly outnumber prematurity (37%) as the underlying cause of death for the first time in Delaware FIMR history.

Placental abruption	Preeclampsia 6	PPROM 4
Chorioamnionitis 9	Preterm labor ⁴ Incompetent cer	Pre- existing diabetes 2

Figure F2: Underlying Cause of Death

Contributing factors identified in fetal death cases



Underlying cause of death in infant cases



Among fetal deaths, 39% occurred before 28 weeks gestation. These early stillbirths made up a higher proportion of 2021 FIMR fetal death cases compared to prior years of FIMR review. For example, in 2020 FIMR cases, only 27% of fetal cases occurred before 28 weeks gestation. The average gestational age for fetal deaths was 30 weeks gestation in 2021, similar to the average gestational age of infant deaths at 31 weeks. For additional details, see the <u>CDRC 2021 data addendum</u>.

Among infant cases reviewed, eight infants (42%) survived beyond 28 days of life and thus represent postneonatal deaths. Eleven infants (58%) were neonatal deaths occurring before 28 days of age, including five infants (26%) who died within a few hours of birth.



FIMR Process

In 2021 the random triage process of selecting cases by even/odd date of death was reinstated. This was done to reduce the backlog of cases for review while minimizing the introduction of selection bias. In addition, FIMR staff attempted to contact all women who met the criteria for FIMR regardless of the date of death. If the parent accepted an interview, their case was automatically included for full FIMR deliberation, thus bypassing the date of death triage criteria. In 2021, eight mothers (13%) accepted a maternal interview, including six Black women and two Hispanic women. The CDRC staff procured access to telephonic interpretation to enhance their ability to offer maternal interviews to non-English speaking parents. Family interviews are an important part of the FIMR process and help put forth the parent's perspective on the care they received, any challenges to accessing care, and the quality and content of the care.

The FIMR CRTs also began more consistently documenting findings and strengths during case deliberation and in accordance with NCFRP guidance in 2021. A finding is a systems issue identified relating to an objective familial or patient risk factor. A strength is a systems issue identified relating to a protective factor. Forty FIMR cases (68%) had at least one system finding documented at the time of review, and 39% of cases (n=23) had at least one system strength documented. Table F1 shows the category area of the 92 individual findings and 30 strengths identified in FIMR cases. The category of family support, relating to bereavement support, patient-provider communication, and medical decision-making support, was the most common category for both findings and strengths. Below, some category areas are described in more detail. All categories are included in the <u>CDRC 2021 data</u> addendum with more details on the risk or protective factors identified in FIMR cases.



Findings and strengths were reviewed at the annual FIMR retreat to consider the entire year's worth of cases together. The findings and strengths form the basis of the recommendations put forth in the updated FIMR-MMR Action Plan presented here and shared with CDRC partners throughout the state to improve the maternal and child care system.

			Number	Number
	Category	Definition	of Findings (n=92 total)	of Stregnths (n=30 total)
Ħ,	Family support	Issue relating to providing a family with bereavement support, support in making medical decisions impacting their care or the care of their infant and/or effective patient-provider communication.	32	14
Ø	Continuity of care	Issue relating to a family accessing care when they want it, getting a referral for appropriate care, or the effective communication between providers at different sites to coordinate a family's care, referral or follow up.	16	6
**	Behavioral health	Any isusue relating to a mental health condition, substance use disotrder or evidence of increased stress in a family's life.	10	4
۲	Covid	Any issue relatiing to the direct or indirect impact of Covid infection, or the pandemic response that may have resulted in disruptions in care, stress or hardship to a family.	8	2
~	Physical health	A phsyical health condition affecting the mother before, during or after pregnancy.	6	0
an ^e	Infant health	A physical health condition affecting the infant after birth.	6	1
0	Family planning	Any issue relating to the provision of family planning services or education about family planning options.	3	0
-	Family social risk	The assessment of risk factors pertaining to adverse adult, maternal or childhood experience and/or the provision of support or referrals based on a risk factor identified.	3	1
S	Fetal kick counts	Any issue relating to the effective provision of education on fetal movmement tracking after 24 weeks gestation.	1	2
<u>89</u>	FIMR process	Any issue that effects the timely and thorough review of FIMR cases such as case identification, medical record retrieval and data collection.	7	0

Table F1: FIMR Findings and Strengths by Category Area



Family support

The perinatal period is a time when families are presented with a lot of information. Particularly if a mother has a pregnancy complication or a sick newborn, the amount of medical information and decisions to make can be overwhelming. While this is a time when families are often in more regular contact with the healthcare system, sometimes communication and support are not offered in a way that families can access. Many findings from FIMR cases relate to instances when provider-patient communication was ineffective. In some cases, providers or clinic staff did not know that a family had experienced a fetal or infant death upon postpartum follow-up. Something was said that might have been retraumatizing to the parent. Strengths in the family support category were most often related to excellent palliative care services offered for an impending infant death. Even in the time of Covid, there were many cases documenting hospital or clinic staff providing compassionate support to a grieving family or trying to connect the family to services.



Continuity of care

Home visiting as a longitudinal family support continues to be rare in FIMR cases, as noted in prior years. While the CRTs deemed that 61% of FIMR parents may have benefited from enrollment in a home visiting program, only 4% of families received a referral to such services. The CDRC Home Visiting Committee concluded its work in 2021 and released a <u>final</u> <u>report</u> to the Commission in March 2022. The text box below offers a brief overview of the committee's objectives and key recommendations.

The perinatal period often involves transitions in the point of care and different sites of care: the primary care or well-woman clinic, the obstetric clinic, hospitals, and pediatric clinics. Care can also span different specialties, especially if a woman has medical, obstetric, or behavioral health issues that warrant different expertise. Navigating the various sites, providers, and options for care is a difficult task for families that only became more complex and uncertain during the Covid pandemic. Among the FIMR 2021 cases, 37% of women entered prenatal care late, an increase from prior years. The proportion of women attending their postpartum visit was stable at 61%. Findings in the continuity of care category document the delays in entering or accessing care or transitioning between different sites of care. Sometimes the issue was related to families moving, a period of incarceration followed by re-entry, or a lack of health insurance. Strengths were examples of well-coordinated care between various providers or staff facilitating a referral to another site of care.

Home Visiting Committee Report

At the February 2019 quarterly CDRC meeting, review of the CDRC annual report data highlighted high-risk families' ongoing underutilization of home visiting services. The Commission accepted a motion to establish a Home Visiting (HV) Committee with the following charge: to overcome barriers to establish a HV service system for at-risk families. The committee shall address referrals, services, funding, and outcome measures.

Once established, this core HV committee reviewed previous recommendations from the Child Protection Accountability Commission (CPAC) and the CDRC from the 2018 Joint Commission retreat. In addition, the core group conducted research on national and local best practices for home visiting. The goal of the full report was to develop strong recommendations to address the barriers in providing Delaware families with evidencebased home visiting services. The recommendations put forth highlight a need for resources and systems improvement to make the services readily available to all Delaware families and alleviate referral gaps. The committee identified several areas for continued improvement, and the final committee report is available <u>here</u>.

HV Committee recommendations include the following:

- 1. The State of Delaware should increase funding to expand the current evidencebased or promising practice home visiting programs.
- 2. The Division of Public Health shall establish a full-time Home Visiting Outreach Director position or an Office of Home Visiting.
- 3. The Department of Education should consider embedding Parents as Teachers programs into childcare centers.
- 4. The Department of Services for Children, Youth, and Their Families shall include eligible evidence-based home visiting programs in their state implementation plan of the Family First Prevention Services Act.
- 5. The Delaware Perinatal Quality Collaborative should work with Delaware birthing hospitals to implement policies that allow nurses to educate and refer parents to home visiting based on presenting high-risk concerns.
- 6. The Division of Public Health should review this report and utilize it as a reference when writing their future Home Visiting Annual Report.

Behavioral health

While there were increases in obstetric and physical health risk factors in the 2021 FIMR casecohort, the prevalence of behavioral risk factors experienced by FIMR mothers was similar in 2021 cases compared to prior years. One-third of women had a history of mental illness (33%, n=20), one in five experienced mental illness during pregnancy (20%, n=12), and about one in three had a mental health



condition—most often depression—in the postpartum period (29%, n=17). Eleven women (18%) had a current substance use disorder, and eleven women had a positive urine drug screen at some point in their pregnancy. The most common illicit substance found on urine testing was marijuana. As reported in prior years, 2021 findings documented a few instances when a woman discontinued her psychotropic medication without consulting a provider. Another common theme in behavioral health findings was difficulty accessing care. Strengths noted examples of providers facilitating access to behavioral health care. For more details and a complete list of behavioral health factors captured on FIMR cases, see the <u>CDRC 2021 data addendum</u>.

Physical Health

The health of mothers is a major factor in the health of their pregnancy and its outcome. FIMR cases from 2021 saw an increase in certain known risk factors for poor pregnancy outcomes. More FIMR mothers (22%) had pre-existing hypertension before their pregnancy compared to prior years of review. While pregnant, more women also experienced obstetric complications, including:

- Placental abruption 30%
- Chorioamnionitis 43%
- Preeclampsia 25%
- Oligohydramnios or polyhydramnios 33%

These risk factors were all increased compared to prior years of FIMR cohorts. (See the CDRC 2021 data addendum for a complete list of maternal physical health factors captured by the year of review.) In addition, six women (10%) had a condition that met the criteria for severe maternal morbidity, most often obstetric hemorrhage as defined by transfusion of at least two units of packed red blood cells. One FIMR case was also a maternal death and was reviewed by the MMRC.





Impact of Covid

Among the cases reviewed, 22% of the FIMR deaths occurred during the period of the stay-athome order in Delaware, March-June 2020. Ninety percent of cases occurred after the onset of the COVID-19 pandemic. In half of the cases, there was some documented indication of a significant disruption to the families' lives, most often due to changes in employment, medical care, or living situation. No birthing parents were known to have Covid infection in the 2021 FIMR cohort. There was one case of Covid infection in the immediate family. In one-third of cases, there was evidence of some indirect impact of Covid. In one-third of cases, there was no documented impact of Covid, and in the remaining one-third of cases, FIMR CRTs could not assess the impact of Covid. Findings on Covid relate to increased stress on families, families moving and not having care established, or experiencing a delay in accessing care because of staff shortages. Strengths were instances when hospital staff worked with families to allow additional visitors to meet a sick infant while trying to comply with safety guidelines.



COVID-19 Impact

The indirect impact of Covid was evident in 1 out of 3 FIMR cases due to changes in the way medical care was being delivered with the use of telehealth services, increased family stress and isolation and pressures on healthcare staff.



National FIMR: Strategic Storytelling

In 2021 the CDRC was awarded the opportunity to participate in the National FIMR Storytelling Learning Collaborative. The FIMR Storytelling Project explores how strategic storytelling can strengthen FIMR by combining data and community engagement to further the core objective of reducing the burden of preventable fetal and infant deaths. Stories help humanize and heal, deepen understanding, and motivate action for systems change. They are a way to honor families' lived experiences, address health equity and broaden the dialogue around what is happening in our communities and, most importantly, why.

The CDRC team participated in the four-month collaborative with five other teams from around the U.S. NCFRP coaches provided background and rationale on why stories are important to this work and helped teams begin to tell their personal stories. The CDRC team developed common agreements to create a safe space in meetings for feeling heard and speaking one's truth, important ground rules for doing the hard work of fatality review in a multidisciplinary setting. These "touchstones" will be shared with FIMR and MMR panels in the near future. As a result of this initial work, the CDRC staff also requested Commissioners and fatality review panel members to answer a brief survey about why they do this work. The survey results are included in Figure F3: Strategic Storytelling and get at *Our Why's*: "why do we participate in fatality review?"





Figure F3: CDRC and panel members on why they do this work





Maternal Mortality Review: 2021

Delaware is one of 31 states receiving support from the CDC Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) grant to standardize national data collection and in-depth review of pregnancy-associated deaths. The five-year grant has enabled MMR to have a dedicated MMR Coordinator and participate in CDC technical assistance and multistate workgroups to advance practices for more complete reviews. The MMR Committee (MMRC) is a multi-disciplinary group that reviews each pregnancy-associated death occurring among Delaware residents to answer the following key questions:

- Was the death pregnancy related? That is, if the woman had not been pregnant, would she have died? If the answer is no, then the death is pregnancy-related.
- 2. What was the underlying cause of death?
- 3. Was the death preventable?
- 4. What were the circumstances surrounding the death?
- 5. What are the findings that address the contributing factors?
- 6. What recommendation can be made to prevent a similar death in the future?

Definition: **Pregnancy associated death**

The death of a person while pregnant or up to one year after the end of the pregnancy, irrespective of cause.

In 2021, the MMRC reviewed 11 cases of pregnancy-associated deaths occurring in the calendar years 2019 to 2021. The women ranged in age from 20 to 40 years of age. Family interviews were available for five out of the 11 cases (45%). These interviews are extremely rich sources of detailed information that give insights into the woman's life experiences and experiences getting the care and support she needed. The interviews offer an important balanced perspective to the medical and social service records abstracted and synthesized into a de-identified case summary. Among the 2021 MMR cases, four deaths were determined to be pregnancy-related, and four deaths were pregnancy-associated but not related. The MMRC could not decide on pregnancy relation in three cases. The timing of death was as follows: two deaths occurred while the woman was pregnant, three deaths occurred in the early postpartum within 42 days after pregnancy. The majority of deaths (91%, 10 out of 11) were deemed to be potentially preventable. Figure M1 shows the causes of death among the 2021 cases. (For an overview of 2021 MMR cases, see the CDRC 2021 data addendum.)

As part of case deliberation, the MMRC checks if any one of four factors likely contributed to the death. These four "checkbox" factors are obesity, discrimination, substance use disorder (SUD), and mental health. Among the 2021 cases, 10 out of 11 had at least one checkbox factor deemed contributory. In most cases, there was more than one factor implicated. SUD was checked in 80% of cases, as evident by the prevailing cause of death being overdose. In most MMR cases—two out of three—SUD and mental health were co-occurring checkbox factors. Discrimination was a checkbox factor in three cases: two where the mother was Black, and one case where the mother had SUD and chronic pain. Recommendations stemming from the finding of discrimination identify the need for



ongoing staff training on implicit bias, establishing collaborative relationships with patients, and promoting shared decision-making.

Overdose ⁸	Cardiomyopathy 1
	Sepsis
	Suicide

Figure M1: Cause of death, 2021 MMR cases (n=11)

The MMRC also identifies factors at the patient or family, provider, facility, system, and community levels that may have contributed to the outcome from a standardized list of defined risk factors. Figure M2 shows the number and level of the risk factors identified in the 11 cases reviewed. On average, there were eight contributing factors identified per case. Table M1 lists the top contributing factors by level. In 2021, for the first time in MMR reporting, the most common patient/family risk factor was lack of social support/isolation. This was followed by substance use disorder and then other psychosocial risk factors.



Figure M2: Number of contributing factors identified in

MMR cases by level

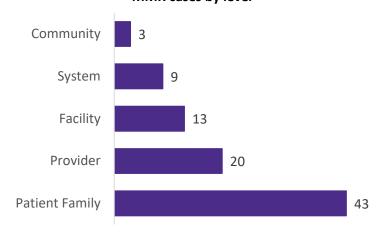




Table M1: Type of contributing factors identified by level

Level	Contributing Factors by order of frequency (n = number of cases)
Patient/Family	Social support / isolation (7), SUD (6), Mental health (4), Violence (4), Childhood trauma (4), Chronic disease (4), Unstable housing (3)
Provider	Clinical Skill / quality of care (5), Communication (4), Assessment (3)
Facility	Delay in diagnosis or care (3), Adherence to policies or procedures (2)
System	SUD (1), Social support / isolation (1), Other*-vital statistics accuracy, referral for autopsy (5)
Community	Public awareness about SUD risk and danger signs of overdose (2)

*Other system factors were not contributory to death but are issues for systems improvement

Impact of Covid

Eight out of the 11 MMR deaths occurred after March 2020 and during the period of the COVID-19 pandemic. Covid was not implicated directly in any case as the cause of death. The MMRC does consider the indirect impact of Covid, and two cases had evidence of the indirect impact of Covid. This will be a topic for continued study and analysis in MMR data over the next few years.

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Review to Action

Maternal Urgent Warning Signs Project

Some of the pregnancy losses and pregnancy-associated deaths experienced by Delaware residents have been related to a lack of knowledge of pregnancy complications and the ability to communicate the urgency of an issue to their providers. To address this problem, the MMR staff has collaborated with the DPQC and the DHMIC to develop an educational handout and a poster to offer birthing and post-delivery persons. It will be shared with community healthcare providers, including community health workers and doulas, to ensure their understanding of potential complications, and they will be encouraged to share the information with their clients. The materials will be available in multiple languages and at a reading level to promote understanding of health information. These materials will be made available in 2022.





Maternal Mortality Review: 2017-2021

Since Delaware has only about 10,000 live births per year and 5-10 pregnancy-associated deaths annually, it is helpful to look at several years of data to quantitatively analyze pregnancy-associated deaths and report key statistics. Over the last five years, from 2017 to 2021, the MMRC reviewed 35 cases. They determined that 1 in 4 cases (26%, n=9) were likely pregnancy-related, meaning the woman's death was causally linked to her pregnancy. Twenty-one cases (60%) were pregnancy-associated but not related (PANR), and pregnancy relation was unable to be determined (UTD) in 5 cases (Figure M3).

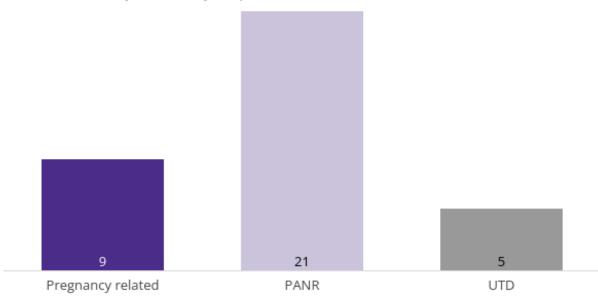


Figure M3: Pregnancy relation for cases reviewed 2017-2021

Maternal race and ethnicity differed markedly between pregnancy-related cases and PANR or UTD cases. As shown in Figure M4, Black non-Hispanic women were more likely to die of a pregnancyrelated cause compared to White non-Hispanic women. While Black women made up 28% of Delaware live births in 2019, they represent 78% of pregnancy-related cases over the 2017-2021 period. These findings align with national trends that report a three-fold higher pregnancy-related mortality ratio for Black non-Hispanic women compared to White non-Hispanic women in the US from 2014-2017.⁸ The racial disparity among PANR/UTD deaths is not as marked compared to the racial composition of women of childbearing age in the Delaware population as a whole. Black non-Hispanic women make up 38% and 31% of these two groups, respectively.

⁸ CDC, Pregnancy Mortality Surveillance System. Available at: <u>https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm</u>. Accessed April 18,2022.

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Pregnancy-related mortality ratio

The Delaware pregnancy-related mortality ratio (PRMR) for calendar years 2015-2020 was 17 deaths per 100,000 live births (95% confidence intervals: 9, 31). This is on par with the US average PRMR of 17 over 2015-2017.

The PRMR for Black women in Delaware was **3 times higher** than the total population at 52 deaths per 100,000 (95% confidence intervals, 24, 99).

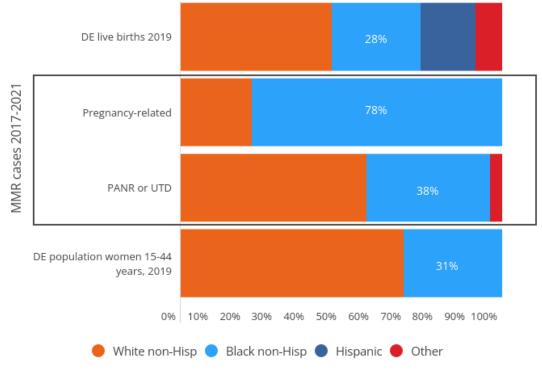


Figure M4: MMR cases by pregnancy relation and race/ethnicity

The box outlines cases reviewed by the MMRC in 2017-2021. For comparison, the race and ethnicity composition of the 2019 Delaware live birth cohort is shown. This group serves as a comparison for the pregnancy-related group. For the PANR or UTD group, the closest comparison is the total population of Delaware women of childbearing age. The percentages shown are the percent of each group identified as Black non-Hispanic women.

Source: Delaware Health Statistics Center. <u>Delaware Vital Statistics Annual Report, 2019</u>. Delaware Dept of Health and Social Services, Division of Public Health, 2021.



Timing of death also varies by pregnancy relation. A larger proportion of pregnancy-related cases (44%) occurred in the immediate postpartum period, within 42 days of the end of pregnancy. In contrast, two out of three PANR or UTD cases (65%) occurred in the late postpartum period 43-365 days after the end of pregnancy (Figure M5). However, the proportion of potentially preventable cases did not differ between pregnancy-related and PANR or UTD cases. Overall, over 80% of cases were determined to be potentially preventable in both groups (Figure M6).

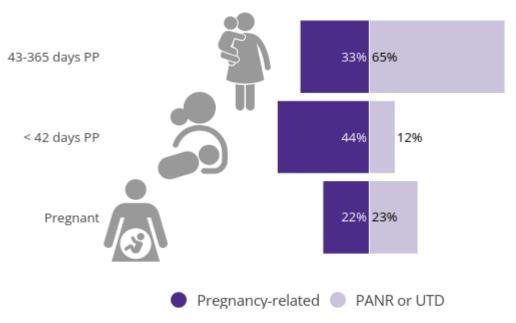
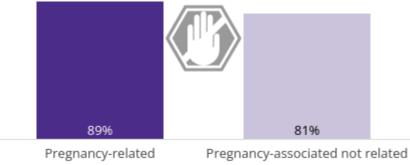


Figure M5: Timing of death by pregnancy relation

Figure M6: Percent of potentially preventable cases by pregnancy relation



or UTD



Overdoses were the most common cause of death in pregnancy-related and PANR/UTD groups (Figure M7). The prominence of overdose as a cause of death in MMR corresponds to Delaware's high overdose death rate in its overall population. In 2020, Delaware had the third-highest overdose death rate in the US at 47 deaths per 100,000 population.⁹ Among MMR cases, after overdoses, the other causes of death did vary, with more medical causes represented in the pregnancy-related group. Overall, in 2017-2021, two deaths were due to homicide and one suicide death reviewed by the MMRC.

Factors checked as contributing to the death were most often both SUD and mental health. In two out of three deaths reviewed in the last five years, either SUD or mental health was implicated in the death (Figures M8 and M9). Most often, these issues were co-occurring. As shown in Figure M10, in the 22 cases with SUD contributing, 15 of them also had a mental health condition likely contributing to the death. This high prevalence of co-occurring mental health and SUD point to the need for addressing both conditions simultaneously wherever a woman accesses care for either condition.



⁹ National Center for Health Statistics. Drug Overdose Mortality by State. Available at: <u>https://www.cdc.gov/nchs/pressroom/sosmap/drug_poisoning_mortality/drug_poisoning.htm</u>. Accessed April 18, 2022.

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Figure M7: Overdose as a percent of all causes of death by pregnancy relation

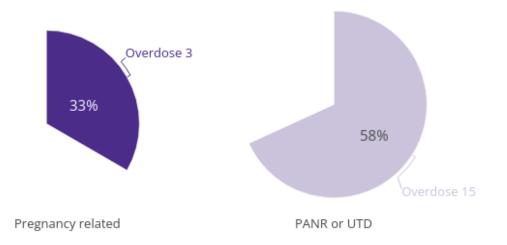


Figure M8: The percent of 2017-2021 cases with SUD checked as a contributing factor overall and by pregnancy relation

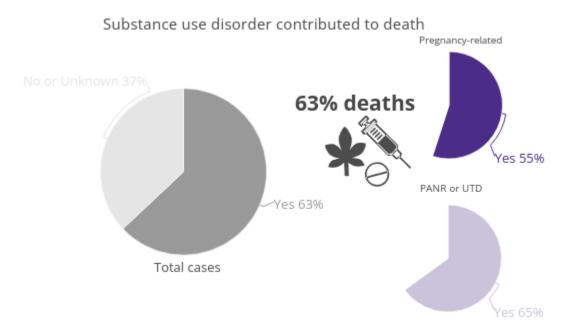




Figure M9: The percent of 2017-2021 cases with mental health checked as a contributing factor overall and by pregnancy relation

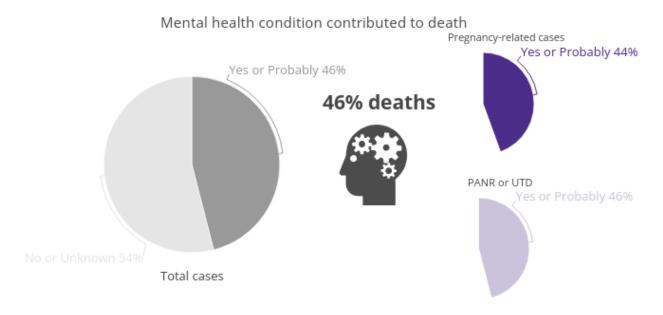
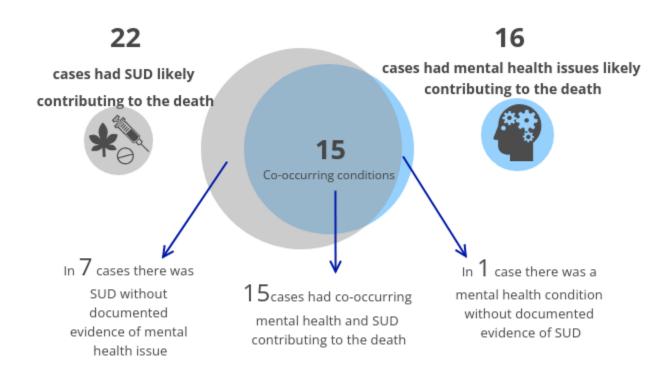


Figure M10: The overlap between SUD and mental health conditions as contributing to MMR deaths (n cases)

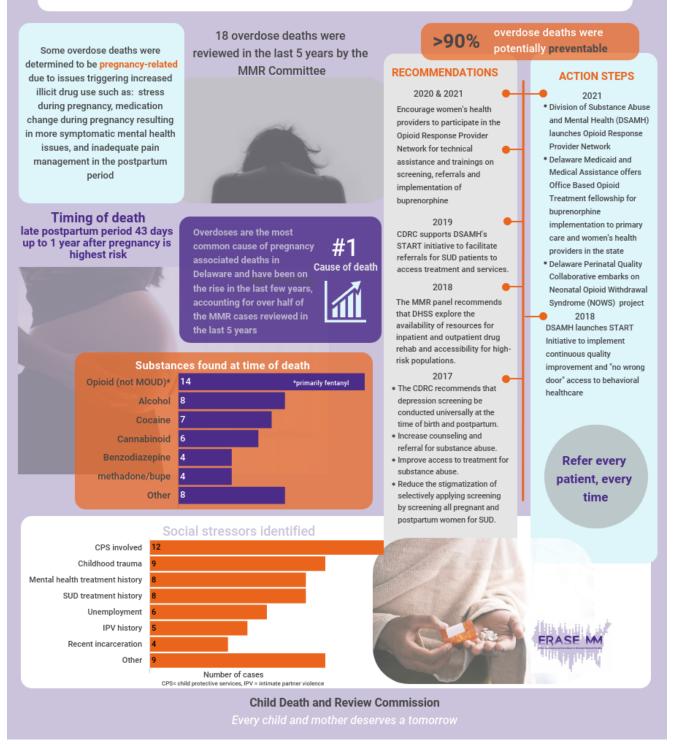


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Figure M11: Findings from overdose deaths reviewed by the MMRC 2017-2021 (n=18)



Overdose deaths 2017-2021







FIMR and MMR Action Plan

The FIMR and MMRC members met in February 2022 to revise and update the joint FIMR-MMR Action Plan developed in February 2021 based on the data and findings from the 2021 case reviews. Below are the priority goals and action steps for implementation. Not shown here, a timeline and lead agencies are also identified for each action step. It will take the CDRC and its partners in the state working collaboratively to make progress towards these goals.

Updated FIMR-MMR Action 2021-2022

- System Area: Documentation
 Goal: Improve documentation issues on patient status and communication of standards across
 hospitals and provider sites.
 - Action: The CDRC will work on a one-page infobrief to increase provider awareness on the completeness of psychosocial screenings and referrals as documented in CDRC cases. This infobrief will be shared with the Medical Society of Delaware and Delaware chapter of the ACOG for their distribution to members.
 - Action: Standardize medical transport forms.
 - Update: The forms are complete and include a home birth to hospital and hospital to hospital versions. The forms will soon be uploaded to the DEthrives.com website.

2. System Area: Insurance

Goal: Improve obstetrical evidence-based care statewide that is covered by insurance.

- Action: Birth hospitals and large practices should consider employing an obstetric navigator to improve care coordination for women with multiple comorbidities. These navigators would have the ability to screen and refer to home visiting programs and ideally would use Z codes for reimbursement through Medicaid.
- Action: Consider funding a perinatal nurse educator to assist the DPQC with providing guidance and training for providers.

3. System Area: Social Determinants of Health

Goal: Ensure that all providers provide care through a trauma-informed approach and social determinants of health lens.

- Action: Promote training and resource materials from expert sources on implicit bias and communication with patients on sensitive or difficult topics.
 - Update: An educational video production of this provider training was filmed in July 2021. Video editing will take place in Fall 2022. The projected release of the first of the four training webinars will be in early 2023.
- Action: Providers/hospitals will screen for/review adverse childhood and adult events, including housing and food access insecurity, provide appropriate support, and, when necessary, offer referrals for services.



4. System Area: Education

Goal: Increase knowledge and awareness by providing ongoing training for providers on maternal and fetal/infant mortality issues.

- Action: Reach out to primary care providers and behavioral health providers to offer informal discussions on "ask the experts" over the next 18 months to enhance provider confidence in caring for pregnant women in various settings. A specific topic to cover will be the appropriate use of psychotropic medications in pregnant patients to ensure optimal mood and anxiety disorders management.
- Action: Develop a list of bereavement specialists who can work with family practice, medical residency, and nurse education programs to offer educational talks on grief and family support strategies.
 - Update: The CDRC has hired a bereavement specialist who has compiled and distributed the list. It will be placed on the CDRC website in May 2022. The bereavement specialist has started to work on virtual on-demand educational training.
- 5. System Area: *Care Coordination / Communication*

Goal: Optimize care coordination across all domains and providers for high-risk women.

- Action: Birth hospitals and large practices should consider employing an obstetric navigator to improve care coordination for women with multiple comorbidities. These navigators would have the ability to screen and refer to home visiting programs and ideally would use Z codes for reimbursement through Medicaid.
- Action: Encourage women's health providers to participate in the Opioid Response Provider Network over the next year and take advantage of technical assistance to screen and refer for mental health and SUD.
 - Update: This work is ongoing with the partnership of the DSAMH and DMMA. Training on the special needs of pregnant and parenting women has been included in DSAMH learning collaboratives. The DMMA hosted a regional SAMHSA conference in February 2022 on "*Clinical guidance for treating pregnant and parenting women with opioid use disorder and their infants*." Over 300 participants attended the virtual conference.

6. System Area: Housing

Goal: Improve housing availability for pregnant women.

- Action: Support and provide data and findings from CDRC reviews to inform the Healthy Beginnings at Home pilot, a DHMIC's Social Determinants of Health Committee project.
- 7. System Area: Home Visiting

Goal: Improve home visiting participation for high-risk women

Action: The CDRC completed the work of its Home Visiting Committee. The report was released in March 2022 and is available on the <u>CDRC website</u>. The CDRC staff continues to participate in the Home Visiting Community Advisory Board to follow up on the recommendations and findings of the committee report.





8. System Area: Health Equity

Goal: Create the conditions for inclusive, meaningful engagement with communities disproportionately affected by maternal and child mortality to improve health outcomes.

Action: The CDRC shall establish a workgroup under the MMRC to analyze and implement recommendations from the Black Mamas Matter Alliance report <u>Maternal</u> <u>Mortality Review Committees: Sharing Power with Communities (Nov 2021)</u> to improve internal processes of review, community engagement, transparent reporting of data and findings and hold ourselves accountable for inclusive, equitable dialogue to address the root causes of excess, preventable mortality.







Conclusion

Data and findings from the 2021 cases reviewed by the CDRC and its three fatality programs reveal the ongoing challenges faced by vulnerable families in the state, particularly in light of the COVID-19 pandemic. While Covid was rare as a direct cause of death in CDRC cases, its indirect impact is being more widely felt, as seen in the CDR/SDY findings on the youth mental health crisis, more late entry into prenatal care, and physical and obstetric complications among FIMR cases, and social isolation and rising overdoses among MMR cases. It will take a few more years to unpack the fuller impact of Covid and its resulting changes to how the health care system functions. CDRC fatality review programs, with its multi-disciplinary teams, are in a unique position to add to the state and national discourse on the fuller evaluation of the impact of Covid. It will continue to take the CDRC engaging with its partners to implement the recommendations from fatality reviews. It will also take some re-envisioning to engage more diverse stakeholder groups spanning the range of community, social and behavioral health services to meet the needs of families and strengthen their connections to care. This is work essential to the fulfillment of the CDRC's mission. It is why we do what we do.





Commissioners and Review Panel Members

The State Attorney General 31 Del. C. § 321 (a) Jim Kriner, Esq., Deputy Attorney General, Designee	The State Medical Examiner 31 Del. C. § 321 (a) Gary L. Collins, MD.		
The Secretary of the State Department of Health and Social Services 31 Del. C. § 321 (a) Currently Vacant	The Director of the Division of Public Health 31 Del. C. § 321 (a) Mawuna Gardesey, Public Health Administrator, Designee		
The Secretary of the State Department of Services to Children, Youth, and Their Families 31 Del. C. § 321 (a) Trenee Parker, Director, Division of Family Services Designee	The Chief Judge of the Family Court 31 Del. C. § 321 (a) The Honorable Joelle Hitch, Judge, Designee		
Office of the Child Advocate 31 Del. C. § 321 (a) Tania Culley, Esq., Child Advocate	The Superintendent of the Delaware State Police 31 Del. C. § 321 (a) Corp. Andrea Warfel, Designee		
Chair of the Child Protection Accountability Commission 31 Del. C. § 321 (a) Jennifer Donahue, Esq., Investigation Coordinator, Designee	A representative of the Medical Society specializing in Pediatrics 31 Del. C. § 321 (a)(1) Amanda Kay, MD, MPH		
The State Secretary of Education 31 Del. C. § 321 (a) Susan Haberstroh, Director, Policy and External Affairs Designee	A representative of the New Castle County Police Department 31 Del. C. § 321 (a)(5) Lt. Michael Bradshaw, Family Services Unit		
A representative of the Medical Society specializing in Neonatology 31 Del. C. § 321 (a)(1) David A. Paul MD, Pediatric Chair at Christiana Care	Two Child Advocates from State-wide Nonprofit Organizations 31 Del. C. § 321 (a)(6) Vacant Mary Ann Crosley, Visiting Nurses Association		



A representative of the Medical Society	A representative of the Police Chief's
specializing in Obstetrics	Council of Delaware who is an active Law
31 Del. C. § 321 (a) (1)	Enforcement Officer
Philip Shlossman, MD.	31 Del. C. § 321 (a)(4)
	Chief Laura Giles, Elsmere Police
	Department
A representative of the Medical Society	A Chairperson of each Regional Child Death
specializing in Perinatology	Review Panel
31 Del. C. § 321 (a)(1)	31 Del. C. § 321
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Commission	Kate Cronan, MD, SDY Advanced Chair
	Amanda Kay, MD, SDY Co-Chair
	Philip Shlossman, MD, CDR Panel Chair
A representative of the Delaware Nurses	A Chairperson of the Maternal Mortality
Association	Review
31 Del. C. § 321 (a) (2)	31 Del. C. § 321
Nancy Forsyth, R.N.	Garrett Colmorgen, MD, Chair
	Vanita Jain, MD, Co-Chair
A representative of the National	A Chairperson of each Fetal and Infant
Association of Social Workers	Mortality Review Case Team
31 Del. C. § 321 (a) (3)	31 Del. C. § 321 (a)
Fran Franklin, D.S.W.	Aleks Casper, New Castle County Chair
	Bridget Buckaloo, R.N., Kent/Sussex County
	Chair

Theresa M. Covington Award for Excellence in Fatality Review

In 2021 Anne Pedrick, CDRC Executive Director, received this award from the National Center for Fatality Review and Prevention (NCFRP) as a testimony to her spirit of collaboration, innovation and passion. In the words of the current NCFRP Director, Anne's contributions "to the field of fatality review are phenomenal and have impacted teams and professionals throughout the US." She was recognized by her peers and colleagues in fatality review as well as the Chief Justice of the Supreme Court of Delaware: "on behalf of the Judicial Branch, thank you for your contributions to the national dialogue on the prevention of child deaths and your commitment to the most vulnerable citizens of our State." Congratulations Anne!



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