Maternal and Child Health Services Title V Block Grant

Illinois

FY 2021 Application/
FY 2019 Annual Report
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I. General Requirements

I.A. Letter of Transmittal

To be added when application officially submitted.

I.B. Face Sheet
The Face Sheet (Form SF424) is submitted electronically in the Health Resources and Service Administration (HRSA) Electronic Handbooks (EHBs).

I.C. Assurances and Certifications
The State certifies assurances and certifications, as specified in Appendix F of the Appendix of Supporting Documents for 2020 Title V Application/2019 Annual Report Guidance, are maintained on file in the States’ MCH program central office and will be able to provide them at HRSA’s request.

I.D. Table of Contents
This report follows the outline of the Table of Contents provided in the “Title V Maternal and Child Health Services Block Grant To States Program Guidance and Forms,” OMB NO: 0915-0172; Expires: December 31, 2020.

II. Logic Model
Please refer to figure 4 in the “Title V Maternal and Child Health Services Block Grant to States Program Guidance and Forms,” OMB No: 0915-0172; Expires: December 31, 2020.
III. Components of the Application/Annual Report

III.A. Executive Summary

III.A.1. Program Overview

Title V of the federal Social Security Act of 1935, also known as the Maternal and Child Health (MCH) Services Block Grant, is the oldest federal-state partnership to support the health and well-being of all mothers, children, and families, including those with special health care needs.

Illinois' Title V Maternal and Child Health Services Block Grant Program is administered by the Illinois Department of Public Health (IDPH), Office of Women’s Health and Family Services, Division of Maternal, Child, and Family Health Services. A subaward, as specified in state statute, is provided to the University of Illinois at Chicago Division of Specialized Care for Children (UIC- DSCC) to develop and administer programming for children and youth with special health care needs (CYSHCN). The annual Title V allocation for Illinois is approximately $21 million.

The Office of Women's Health and Family Services (OWHFS) is one of six programmatic offices within IDPH. The vision of OWHFS is “a future free of health disparities, where all Illinoisans have access to continuous high-quality health care.” The mission of OWHFS is to “improve health outcomes of all Illinoisans by providing preventive education and services, increasing health care access, using data to ensure evidence-based practice and policy, and empowering families.” OWHFS houses three divisions: Division of Maternal, Child and Family Services, Division of Women's Health Services, and Division of Population Health Management. These divisions work together closely and are united by a common vision and mission to support women's and family health across the lifespan.

UIC-DSCC has administered Illinois’ CYSHCN programs for more than 80 years. UIC-DSCC envisions that “children and youth with special health care needs and their families will be at the center of a seamless support system that improves the quality of their lives” by partnering with Illinois families and communities to help children and youth with special health care needs connect to the services and resources they need.

Role of IL Title V

A state’s Title V Program is viewed as a leader within the Maternal and Child Health field, convening stakeholders, disseminating data, and implementing best practice programs to improve population health. Title V leadership sit at many state and local tables to ensure that priorities are aligned and that opportunities to utilize Title V funds are leveraged appropriately. In addition, it uses its position to assist in health care systems issues, such as quality of services, adequacy of insurance, improving health literacy, and reiterating the importance of addressing the social determinants of health in the MCH population.

Illinois has a large, complex, and inter-related portfolio of maternal and child health programs that span the life course from pre-conception through adulthood that support primary, secondary, and tertiary direct, enabling, and infrastructure-building interventions. Title V is the only commitment of federal resources with a mission broad enough to encompass this full range of activity and provide a framework for integrating them into a coherent system that benefits all women, infants, children, adolescents, young adults, and CYSHCN.

In July 2013, Illinois’ IL Title V was transferred from the Illinois Department of Human Services (DHS) to IDPH, representing a shift from targeted direct services to a population-health perspective. One prime
example of population health programming includes funding the regional perinatal health program which supports ten administrative perinatal centers to provide training, support, and technical assistance to an assigned network of the state’s birthing hospitals. This program positively impacts virtually 100% of mothers giving birth in Illinois hospitals and their infants.

UIC-DSCC uses the six core outcomes of systems of care specified by the federal Maternal and Child Health Bureau (MCHB) for CYSHCN as its framework for needs assessment and priority setting. Review of state and national data indicate that care coordination and transition remain important priorities for Illinois’ CYSHCN. Currently, UIC-DSCC provides care coordination services through two programs. The Core Program serves CYSHCN who are under 21 years of age, reside in Illinois, and have any of 11 system-based categories of health impairments. Financial assistance (filling gaps in health insurance) is available to Core Program families with incomes below 325% of the federal poverty standard. The Home Care Program is the single point of entry for medically-complex children who require in-home shift nursing services. UIC-DSCC has an interagency agreement with the Illinois Department of Healthcare and Family Services (HFS) to operate Illinois’ Medicaid waiver for medically fragile and technology dependent children and to coordinate care for less medically-complex children who receive in-home nursing services through the state’s Medicaid program.

Population Needs and Title V Priorities

In 2017, there were 2.5 million women of reproductive age and approximately 145,000 births in Illinois. Illinois is a racially diverse state. Among Illinois resident live births in 2017, approximately 53% were to white women, 17% were to black women, 21% were to Hispanic women, and 8% were to non-Hispanic women of other races (includes Asian, Pacific Islander, American Indian and multiple-race women). In 2017, there were just over 3 million children ages 0-18 years in Illinois, which ranks Illinois as the fifth state with the highest child population.

Approximately, two thirds of the Illinois population reside in Cook County (includes Chicago) and the five surrounding counties. The remainder of the population lives in smaller urban areas or rural areas. There is substantial geographic variation in the availability of health care, which impacts MCH outcomes.

Illinois’ IL Title V identifies needs, priorities, and strategies. These activities were completed through a comprehensive Needs Assessment process conducted every five years. The Illinois’ 2020 Title V Needs Assessment, IDPH and UIC-DSCC in collaboration with the UIC School of Public Health’s Center of Excellence in Maternal and Child Health (CoE-MCH). The process was guided by a framework that included: (1) the assessment of health status, service needs, and system capacity related to each population domain; (2) the development of Title V priorities for 2021-2025; (3) the assessment workforce and agency capacity; and (4) the development of a final Action Plan. Information was gathered through an Expert Panel (EP) and Advisory Council (AC) that provided feedback on the state’s MCH needs, priority selection, and strategy identification; key Informant Interviews with IL Title V Leadership and staff; consumer listening sessions; and surveys designed to determine workforce capacity, assess partners’ views of Illinois Title V’s capacity, and gather public/consumer input.

The ten priorities developed during the Needs Assessment will guide Illinois Title V activities over the course of the next five years (2021-2025) and are provide below by population domain.

Domain: Women/Maternal Health

1. Assure accessibility, availability, and quality of preventive and primary care for all women, particularly for women of reproductive age – women/maternal
2. Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum.
**Domain: Perinatal/Infant Health**

3. Support healthy pregnancies to improve birth and infant outcomes.

**Domain: Child Health**

4. Strengthen families and communities to assure safe and healthy environments for children of all ages and enhance their abilities to live, play, learn, and grow.

**Domain: Adolescent Health**

5. Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors.

**Domain: Children and Youth with Special Health Care Needs**

6. Strengthen transition planning and services for children and youth with special health care needs.
7. Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs.

**Domain: Cross Cutting**

8. Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders.
9. Support an intergenerational and life course approach to oral health promotion and prevention.
10. Strengthen the MCH epidemiology capacity and data systems.

**Title V Partnerships**

Continued collaboration with key stakeholders is essential to Illinois achieving its priorities for the MCH populations. The IL Title V will continue to serve as a convener, assuring that the goals for the IL Title V are aligned with the other projects serving this population, including the Governor’s Office of Early Childhood Development, Healthy Start, the State Health Improvement Plan, Medicaid managed care organizations, and Evidence-Based Home Visiting Programs, such as the Maternal, Infant, and Early Childhood Home Visiting Program (MIEHCV).

Additionally, the IL Title V works with the Illinois Department of Human Services (DHS), the former home of the Title V Block Grant. Not only does DHS provide IDPH with programming for the state match requirements, but also, the two sister agencies collaborate on special projects. For example, DHS is rewriting its administrative rules for several of maternal and child health programs in its portfolio, including the programs used for Title V maintenance of effort and match. The IL Title V is participating in this effort to ensure that the programs implemented are aligned with Title V priorities.

Illinois’ IL Title V further expands its statewide reach through its grant programs that-fund various entities such as school-based health centers, Regional Perinatal Health Program’s ten Administrative Perinatal Centers, Illinois Perinatal Quality Collaborative, State universities, local health departments, and community organizations.

A key benefit of Title V expanding its reach through grant programs is the ability to leverage relationships with local health department, in a decentralize public health system. IL Title Vs provided needed funding for local health departments to develop and implement projects targeted to MCH populations. Two grant programs of interest to the local health departments are the Adolescent Health Initiative and the Well-Woman Care Mini Grant Program. In addition to grant funding, Illinois Title V secures local health department representation on its state level workgroups such as the Perinatal Advisory Committee and the Maternal Mortality Review Committees.
UIC-DSCC also partners closely with state agencies and community-based organizations to coordinate care and strengthen systems for serving CYSHCN. These partners include HFS, IDPH, DHS (which houses Illinois’ Part C Early Intervention, home visiting, and other early childhood programs, behavioral health, developmental disability, and rehabilitation services programs), the Department of Children and Family Services (DCFS, Illinois’ child welfare agency), the Illinois State Board of Education (ISBE), local schools, children’s hospitals, pediatric primary and specialty care providers, licensed home nursing agencies, durable medical equipment vendors, and numerous public health, human service, and allied health care providers. UIC-DSCC leverages these relationships through advisory committees and work groups, clinic attendance, community meetings, and other strategies.

Highlights from the IL Title V
Illinois was one of the first states to implement maternal mortality review and created the state Maternal Mortality Review Committee (MMRC) in 2000. A second state committee, the Maternal Mortality Review Committee on Violent Deaths (MMRC-V) was formed in 2015 to review deaths of women who died within a year of pregnancy due to homicide, suicide, or drug overdose.

In 2017, IDPH and Title V re-designed its approach to the review process by strategically shifting to a population-based and systems-based approach. As a result of this re-design, IDPH released its first Illinois Maternal Morbidity and Mortality Report in October 2018. The Illinois General Assembly embraced the report and passed numerous state legislation during the 2019 Legislative Session. One of the most notable developments was the expansion of Medicaid from 60 days to 12 months postpartum. Other legislation focused on maternal levels of care and insurance coverage requirement for mental health conditions that occur during pregnancy or during the postpartum period. Currently, IDPH is preparing a second report covering two additional years of data.

In October 2018 UIC-DSCC along with Ann & Robert Lurie Children’s Hospital hosted the Nitty Gritty Nursing Conference. The intended audience of this conference was nurses who care for medically complex children in the home setting. The conference was developed in response to some issues pertaining to the quality of nursing care provided in the home by nurses serving medically complex children. One key area identified with this issue was that the skills needed to care for this population are above what is taught in nursing school. While the team of experts at Lurie developed the content for this conference, UIC-DSCC has obtained the intellectual rights to this material. Approximately 75 people attended the event in October. UIC-DSCC worked with OSF Saint Francis Medical Center Children’s Hospital of Illinois to create an event in the central part of the state with the using the same content developed by the Lurie team. The Nitty Gritty Nursing Conference was highlighted in a June 2019 Health Affairs article, “Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, & Future Directions,” as a successful example of targeted nurse education. This is a notable example of the IL Title V serving CYSHCN working with state partners to identify systemic issues and provide solutions.

III.A.2. How Federal Title V Funds Support State MCH Efforts

Title V funds enable IDPH to financially support state and local organizations that conduct public health research, evaluate and expand programs, implement quality improvement initiatives, and provide workforce training. In addition, the funds provide flexibility to assess population needs and design innovative programs, such as the Adolescent Health Initiative, which focuses on enhancing adolescents’ access to primary and preventive health care. Another key example of Title V funds supporting state MCH efforts is the Illinois Maternal Mortality Review Committee. Illinois re-designed its approach to the state review by strategically shifting to a population-based and systems-based approach. As a result of this re-design, IDPH released its first Illinois Maternal Morbidity and Mortality Report in October 2018, one of the most notable developments of the report was the state budget including the expansion of Medicaid to one year postpartum and maternal levels of care. Additionally, numerous state legislation passed during the
2019 Legislative Session. This legislation includes the Maternal Levels of Care Act (IL Public Act 101-0447) which charged IDPH with establishing levels of maternal care for hospitals in Illinois that are complimentary but distinct from the perinatal levels of care system; and Maternal Mental Health Insurance Coverage (IL Public Act 101-0386) which requires insurance coverage for mental health conditions that occur during pregnancy or during the postpartum period. Currently, IDPH is preparing a second report covering two additional years of data.

For CYSHCN, Title V funds enable UIC-DSCC to extend independent, comprehensive, person-centered care coordination and gap-filling financial assistance to children and youth with complex health conditions. They also support UIC-DSCC’s capacity for developing better-integrated service systems for all CYSHCN.

III.A.3. MCH Success Story

The Illinois Division of Population Health Management (DPHM), housed in the Office of Women’s Health and Family Services partners with the Illinois Department of Corrections (IDOC) to provide education and support to pregnant women and new mothers and infants housed within two women of the correctional facilities, Logan Correctional Center (LCC) and Decatur Correctional Center (DCC). The education and support consist of pregnancy education, breastfeeding education, and lactation support and counseling. The healthcare staff receive prenatal and delivery education/training as well.

DPHM partnered with IDOC to open the Pregnancy Wing at LCC in March 2019. This wing houses all pregnant women in the facility in one location. In addition, DPHM provided the facilities with new breast pumps, pumping kits, milk storage bags, and breast pads. DPHM is always looking for opportunities to leverage its relationships and bring more services to the population it is serving. During FY2019, DPHM collaborated with the regional Administrative Perinatal Center (APC) to provide additional trainings. The APC’s Maternal & Fetal Medicine (MFM) Physician participated in these trainings and was able to interact with the pregnant women during the healthcare trainings and answer questions as well as begin to identify women who may have been having high risk experiences.

Additionally, obstetrical and neonatal simulation training was provided on multiple occasions at the LCC to nurses, mid-level providers, nursing administration, and a physician. This training allowed for staff to test their obstetrical and neonatal skills and identify areas of improvement to ensure quality care for pregnant women in the justice system.
III.B. Overview of the State

Demographic Information

Population Size and Changes

Illinois is a large, diverse state. It is currently the sixth most populous state in the nation and was home to 12,741,080 residents in 2018. The Chicago metro area is home to 9.5 million people, 2.7 million of whom reside within the city. Chicago is the largest city in Illinois and the third largest in the country. In recent years, both Illinois and the city of Chicago have experienced a population decline; 0.7% of the state population left from 2016-2018, and Chicago lost 0.23% of its population from 2017-2018.

In 2018, nearly one in four (22.4%) Illinois residents were under age 18 — a total of approximately 2.9 million children. Approximately 6% of the total population, 767,348 children, is under the age of five. The fertility rate in Illinois during 2017 was 59.0 births per 1,000 women ages 15-44; the birth rate was 1.73 per 1,000 population. The fertility and birth rates in Illinois are slightly lower than the national averages (60.3 and 1.77 respectively), but higher than several other large states, such as Florida and California.

Geographic Considerations

Illinois’ population is concentrated in Cook County (which includes the city of Chicago) and the surrounding collar counties. More than 65% of the state’s population, 8.4 million people, live in these counties. In addition to diverse and urban Chicago, Illinois is home to many small and mid-sized cities. Twelve cities in the state, including Joliet, Rockford, and Aurora, have more than 75,000 residents.

By land mass, Illinois is largely rural. More than two-thirds of its 102 counties are classified as non-metropolitan, and approximately 1.5 million Illinoisans live in rural communities. Reflecting a larger long-term national trend, all rural areas in Illinois have decreased in population since 2012. Rural communities in Illinois are largely concentrated in the southern and western parts of the state.

In planning for the care and well-being of Illinois’ maternal and child health population, the IL Title V and its partners must balance the needs of large and diverse urban center, several mid-sized cities with unique populations and care delivery systems, and a large rural area with limited geographic access to services.

Education

In 2017, approximately 89% of Illinois adults were high school graduates and 33% were college graduates. Educational achievement is not evenly distributed in the state. Only 84% of adults in Chicago are high school graduates, indicating the need for increased educational focus in this county. Illinois also suffers from racial disparities in educational achievement; 21% of non-Hispanic blacks and 14% of Latinos have graduated from college, compared with 37% of non-Hispanic whites. The rates of high school and college graduation are slightly higher in Illinois than in the U.S.

Racial and Ethnic Diversity

Illinois is diverse in terms of racial/ethnic makeup of the population. In 2017, the majority (62%) of the Illinois population was non-Hispanic white. Non-Hispanic blacks comprise 14% of the population, and Latinos of all ethnicities account for 17%.

Cook County is more racially diverse than the state overall. In 2017 in Cook County, only 43% of the population was non-Hispanic white, while non-Hispanic blacks comprised 23% and Latinos comprised
25%. Within the city of Chicago, this diversity is even more pronounced: 29% were non-Hispanic white, 30% were non-Hispanic black, 29% were Latino, and 6% were Asian. So, while Illinois is more racially homogenous than other large states, the concentration pockets of racial minorities in the Chicago area presents unique challenges for culturally competent health care delivery.

Illinois has a significant population born outside the United States. In 2017, approximately 14% of Illinois residents were foreign born. Most of these foreign-born residents (51%) are not U.S. citizens. Foreign-born Illinoisans come primarily from Latin America, with a sizeable Asian population as well. Reflecting this large immigrant population, more than 23% of Illinoisans speak a language other than English at home, with Spanish being the most common other language. Cook County has a higher percentage of foreign-born residents and non-English speakers than the rest of the state.

Employment and Income

In 2013-2017, 65% of Illinois adults were in the civilian labor force — meaning that they were working or wanted to be working. In 2018, Illinois had a seasonally adjusted unemployment rate of 4.6%. However, due to the COVID-19 pandemic, the non-adjusted employment rate rose from 4.1% in June 2019 to 14.6% in June 2020. The longer-term economic ramifications of the pandemic are not yet known, but there is certainly concern for how the economic downturn will affect women, children, and families.

Most Illinois residents were in occupations categorized as management/professional (38%) or sales/office (24%). The per capita income in Illinois in 2013-2017 was $32,924, compared to a national average of $31,177. Incomes are generally higher in Cook County, with a per capita income of $33,722. Illinois’ per capita income was higher than that in Pennsylvania, Florida, and Texas, but lower than that of New York and California.

Poverty and Housing

In 2017, 13% of all Illinoisans lived below the federal poverty line (FPL). Children are more likely to live in poverty; 17% of children under 18 years old and 18.8% of children younger than five years old lived in poverty. Poverty in Illinois is more common in Cook County, and specifically in the city of Chicago. In Cook County in 2017, 14% of the total population and 20% of children lived in poverty; in Chicago, 19% of the total population and 27% of children lived in poverty. Of all Illinois households in 2017, 13% received food stamps and 2% received cash assistance.

Living in a female-headed household is strongly associated with poverty in Illinois. While 9% of all families were impoverished, 26% of female-headed households in 2017 had incomes below the FPL. This increases for households with children; 35% of female-headed households with children under 18 years old and 40% of female-headed households with children under five years old were impoverished. Mothers, and especially unmarried mothers, are very likely to live in poverty. Nearly half (45%) of unmarried women who gave birth in the last 12 months lived in poverty, compared to only 10% of married new mothers.

Poverty is also drastically different by race/ethnicity in Illinois. Among non-Hispanic white residents, the poverty rate in 2017 was 10%, compared to 26% among non-Hispanic blacks and 15% among Hispanics. Among children, this disparity in poverty is even further demonstrated: 10% of non-Hispanic white children under age 18 lived in poverty, compared to 38% of non-Hispanic black children and 202% of Hispanic children.

In Illinois in 2017, 66% of housing units were owner-occupied. This is a higher rate than in many other large states. However, there is a large racial disparity in home ownership; in the Chicago metropolitan area, 74% of white householders own their home, while only 39% of black householders do. For those families that rent a home, the high cost of rental housing is a concern. In 2017, 45% of families renting a
home spent more than 30% of their income on rent. Low-income families are especially at risk for rental costs that consume large proportions of their household income.

**Key Health Indicators**

According to America’s Health Rankings for 2019, Illinois ranked 26th out of the 50 states on combined measures of health determinants, behaviors, and outcomes. Illinois demonstrated strength on measures such as vaccinations for children (9th), supply of primary care physicians (10th) and dentists (11th), and a low rate of people experiencing frequent physical distress (10th) or mental distress (11th). Illinois did poorly when compared to other states on indicators such as excessive drinking (41st), rate of Chlamydia infections (42nd), and air pollution (48th). For birth outcome indicators, Illinois tended to rank in the middle of the states, coming in at 31st for infant mortality and 29th for low birth weight. The report also indicates some positive trends in Illinois, including a decrease in child poverty over the last five year (20% vs. 16%), a decrease in violent crime since 1990, and an 18% increase in supply of mental health providers in the last two years. Unfortunately, there have also been some trends in the negative direction, including a 63% increase in drug-related deaths over the last five years, and a 19% increase in Chlamydia infections over the last four years.

Maternal and women’s health in Illinois present both strengths and challenges. Illinois has made steady progress on some outcomes, such as its teen birth rate -- in 2018, the rate was 15.8 births per 1,000 women ages 15-19 which represented a 67% decline since 2000 and a 31% decline since 2014. More than three quarters of pregnant women receive a prenatal care visit in their first trimester, and nearly 70% of Illinois women have had a preventative medical visit in the past year.

While 89% of children in Illinois are reported by their parents to be in excellent or very good health, there are 39 states with better child health ratings overall. Only about 4% of Illinois children were uninsured in 2016, one of the lowest rates in the country. The asthma hospitalization rate among children 0-4 had been steadily decreasing since 2011, but in 2018 there was a 10% increase over the 2017 hospitalization rate. This increase appears to have occurred only among non-Hispanic Black children; their hospitalization rate increased 21% from 2017 to 2018. Adolescent mortality related to suicide and motor vehicle accidents are relatively low compared to other states but have been steadily worsening and are of concern in the central and southern parts of the state.

**The State’s Unique Strengths and Challenges**

Illinois has many resources that strengthen and support its capacity to impact the health status of women and children. When all the services provided through IDPH and other state agencies are considered, Illinois has a robust set of services for women and children, including CYSHCN. These interventions are supported by an appropriate set of state statutes and regulations. Illinois also has seven colleges of medicine and a college of osteopathy, three dental schools, and numerous colleges for allied health sciences. These institutions are accompanied by large systems of care, including outpatient settings. Illinois also has nine children’s hospitals and many family practice, pediatric primary care, and specialty care providers. Finally, the University of Illinois Chicago (UIC) School of Public Health has one of the United States’ 13 Centers of Excellence in Maternal and Child Health (CoE-MCH). The state’s Title V has an intragovernmental agreement with the UIC CoE-MCH to provide ongoing epidemiological and data support, and IDPH routinely hosts student interns from this program. Even with these resources, Illinois faces challenges in the improvement of women’s and children’s health. Most of Illinois outside of Cook County and the counties that surround it are health provider shortage areas for primary, dental, and mental health services.

Poverty and inequity have resulted in racial and ethnic disparities in health status. It is important to acknowledge racism as a driving force of the social determinants of health and as a barrier to achieving
health equity and optimal health for all people. The impact of racism on health outcomes is particularly
important for Illinois as it is a racially and ethnically diverse state but remains very segregated. Chicago is
consistently ranked as one of the most racially segregated cities in the United States.

Illinois Department of Public Health Roles and Responsibilities

The Illinois Department of Public Health (IDPH) is one of the longest standing state agencies, established
in 1877 as the State Board of Health. It now has headquarters in Springfield and Chicago, seven regional
offices, three laboratories, and over 1,100 employees. IDPH houses over 200 public health programs
covering the spectrum of diseases/conditions and the entirety of the life course. IDPH’s vision is that
"Communities of Illinois will achieve and maintain optimal health and safety" and the mission is to:
“protect the health and wellness of the people in Illinois through the prevention, health promotion,
regulation, and the control of disease and injury.”

In 2016, IDPH became only the eighth state health department to receive accreditation by the Public
Health Accreditation Board (PHAB). The Title V Needs Assessment was cited as an area of excellence by
PHAB. Specifically, PHAB stated that "Extensive community engagement was elicited through the Title V
Needs Assessment Activity coordinated through the Office of Women’s Health and Family Services,
helping to shape statewide maternal-child health policy development. This activity serves as a model for
other programs in the department for community engagement to support and inform policy." Currently,
IDPH is applying for re-accreditation.

The Office of Women’s Health and Family Services (OWHFS) is one of six programmatic offices with
IDPH. The Deputy Director reports directly to IDPH Director (State Health Officer). OWHFS houses three
divisions: Division of Maternal, Child, and Family Services, Division of Women’s Health, and Division of
Population Health Management. These divisions work together closely to support women’s and family
health across the lifespan. OWHFS’ vision is “a future free of health disparities, where all Illinoisans have
access to continuous high-quality health care” and its mission is to: “improve health outcomes of all
Illinoisans by providing preventive education and services, increasing health care access, using data to
ensure evidence-based practice and policy, and empowering families.” The IL Title V sits within the
Division of Maternal, Child, and Family Health Services, with the Title V MCH Director also serving as the
Division Chief.

Illinois’ System of Care

Population Served

Illinois’ IL Title V covers the full range of the “MCH population,” including women of child-bearing age,
pregnant women, infants, children, adolescents, and CYSHCN. Responsibility for the MCH Program in
Illinois is spread across three agencies: IDPH, UIC-DSCC and DHS. IDPH administers the MCH Block
Grant and MCH programming across the state, while UIC-DSCC primarily focuses on statewide CYSHCN
programming; and DHS oversees many of the direct service MCH statewide programs (e.g., WIC, home
visiting).

IL Title V provides approximately $4.5 million annually to the Chicago Department of Public Health’s
Maternal, Infant, Child, and Adolescent Health Bureau to implement comprehensive, effective, and
innovative programming aligned with the state’s Title V priorities for residents of the state’s largest city,
Chicago.

Health Services Infrastructure

Perinatal Levels of Care
Perinatal regionalization is a strategy to organize risk-appropriate services for pregnant women and neonates according to their medical complexity and needs. Currently, 111 Illinois hospitals have a designation for a perinatal level of care, granted by IDPH, which outlines the populations of infants that can be cared for by the facility and the resources and personnel necessary to provide this care. Each birthing hospital is assigned to one of ten administrative perinatal centers (APC), which provides ongoing training, technical support, and consultation on complex medical issues, as well as helps to coordinate and assure the transport of women or neonates between facilities. Illinois Title V supports the APCs and regulates perinatal designations according to Illinois’ Perinatal Administrative Code.

Children’s Hospitals

Illinois has a large network of children’s hospitals and pediatric specialists. There are nine children’s hospitals in Chicago and additional children’s hospitals in Peoria and Springfield. Through partnerships with UIC-DSCC, children’s hospitals in neighboring states also play a key role in promoting the health of Illinois MCH population. Specifically, there are children’s hospitals in Milwaukee, WI, Madison, WI, Iowa City, IA, St. Louis, MO, and Indianapolis, IN that work with UIC-DSCC.

Integration of Services

Behavioral Health: The federal Center for Medicare and Medicaid Services (CMS) approved a series of behavioral health demonstration projects under a 1115b demonstration waiver to implement Integrated Health Homes as a part of HealthChoice Illinois, the state’s Medicaid managed care program.

Financing of Services

Women and children in Illinois are eligible for publicly subsidized health insurance through Illinois’ Medical Assistance program, which is administered by Illinois Department of Health and Family Services (HFS). The Medical Assistance Program includes both Title XIX and Title XXI.

Necessary medical benefits, as well as preventive care for children, are covered for eligible persons when provided by a health care provider enrolled with HFS. Eligibility requirements vary by program. Most individuals enrolled are covered for comprehensive services such as doctor visits and dental care, well-childcare, immunizations for children, mental health and substance abuse services, hospital care, emergency services, prescription drugs, and medical equipment and supplies. Illinois is a Medicaid expansion state. Under the Affordable Care Act (ACA), eligibility for Medicaid coverage was expanded to adults age 19-64 who were not previously covered. Individuals with income up to 138% of the federal poverty level are eligible.

In Illinois there are several insurance options for children and families. Specifically, All Kids is an Illinois’ program for children who need comprehensive, affordable, health insurance, regardless of immigration status or health condition. The impetus behind All Kids is that every child deserves the chance to grow up healthy. The insurance plans under All Kids, include All Kids Assist, All Kids Share, All Kids Premium Level 1 and 2, and Moms and Babies.

Moms and Babies provides a full range of health benefits to eligible pregnant women and their babies. The program pays for both outpatient and inpatient hospital services for women while they are pregnant, and for 60 days after the baby is born. Babies may be covered for the first year of their lives provided the mother was covered when the baby was born. Moms and Babies enrollees have no co-payments or premiums and must live in Illinois.

Along with All Kids, there is FamilyCare and often the programs are referred to as All Kids/Family Care.
FamilyCare offers healthcare coverage to parents living with their children 18 years old or younger as well as relatives who are caring for children in place of their parents. For all plans, non-pregnant adults must live in Illinois and be U.S. citizens or legal permanent immigrants in the country for a minimum of five years. Children and pregnant women must live in Illinois and are eligible regardless of citizenship or immigration status.

There are approximately 1.6 million children enrolled in All Kids. Families may apply using English or Spanish web-based applications that may be submitted online or downloaded and submitted by United States Postal Service.

Over time, insurance coverage and access in Illinois has been an area of steady improvement. In 2017, 91.5% of the civilian non-institutionalized population was insured. Among children ages 18 and under, this proportion was 96.7%. Rates of insurance were lower among Hispanics and Latinos (81.0%), and foreign-born residents who are not citizens (63%).

Women are more likely than men to have insurance coverage, although almost 10% of women ages 19-44 were uninsured in 2017.

Nearly 70% of people in Illinois use private insurance, either alone or in combination with other insurance carriers. Children are less likely than adults to be covered by private insurance, with 59.2% of children under six and 63.8% of children ages 6 to 18 covered by a private insurance plan. More than one third of Illinois residents (34.2%) are covered by a public insurance plan, and for 21.2% of residents a public insurance carrier is their only insurance coverage. Medicaid plans are particularly important for child populations with 37.5% of children using Medicaid in 2017. Public insurance also reaches many of Illinois’ poor residents; 67.5% of residents below 138% of the federal poverty level use a public insurance plan. In 2017, Illinois’ Medicaid program covered 1.4 million children and the Children’s Health Insurance Program covered 324,282. In combination, nearly 1.8 million children were covered, representing a 3% decline from the covered number in 2016.

The implementation of Medicaid managed care is discussed in the “Health Care Delivery System” sub-section.

State Statutes and Regulations Related to Maternal and Child Health Block Grant and Programs

- In 2015, Section 2310-677 of the Department of Public Health Powers and Duties Law (20 ILCS 2310) was enacted, creating the Neonatal Abstinence Syndrome (NAS) Advisory Committee. This committee is charged with advising and assisting IDPH with identification, treatment, reporting, and improving the outcomes of pregnancies where NAS is a factor.
- The Prenatal and Newborn Care Act (410 ILCS 225) and the Problem Pregnancy Health Services and Care Act (410 ILCS 230) establish programs to serve low-income and at-risk pregnant women.
- The Developmental Disability Prevention Act (410 ILCS 250) authorizes regional perinatal health care and establishes the Perinatal Advisory Committee (PAC). The Regionalized Perinatal Health Care Code (77 Ill. Admin. Code 640) establishes the administrative rules related to perinatal levels in Illinois, including resource and personnel requirements for perinatal levels of designation, data submission, and the designation/re-designation site visit process.
- The Perinatal HIV Prevention Act (410 ILCS 335) sets forth the requirements related to HIV testing and counseling of pregnant women by the health care professionals caring for them.
- The Newborn Metabolic Screening Act (410 ILCS 240), the Infant Eye Disease Act (410 ILCS
215), the Newborn Eye Pathology Act (410 ILCS 223), and the Early Hearing Detection and Intervention Act (410 ILCS 213) authorize health screening for newborns. The Genetic and Metabolic Diseases Advisory Committee Act (410 ILCS 265) created a committee to advise IDPH on screening newborns for metabolic diseases.

- The Illinois Family Case Management Act (410 ILCS 212) authorizes the Family Case Management (FCM) program. The WIC Vendor Management Act (410 ILCS 255) "establish[es] the statutory authority for the authorization, limitation, education and compliance review of WIC retail vendors…"

- Section 5/3-3016 of the Counties Code (55 ILCS 5) requires that an autopsy be performed on children under two years of age who die suddenly and unexpectedly and the circumstances concerning the death are unexplained and that all deaths suspected to be due to Sudden Infant Death Syndrome (SIDS) be reported to the Statewide Sudden Infant Death Syndrome Program within 72 hours.

- The Early Intervention Services System Act (325 ILCS 20) "provide[s] a comprehensive, coordinated, interagency, interdisciplinary early intervention services system for eligible infants and toddlers …"

- Section 5/27-8.1 of the Illinois School Code (105 ILCS 5), requires:
  - Children enrolled in public, private, and parochial schools entering kindergarten or 1st grade, 6th grade, and 9th grade to have a health examination and a tuberculosis skin test if they live an area designated by IDPH as having a high incidence of tuberculosis (105 ILCS 5/27-8.1(1));
  - Children enrolled in public, private, and parochial schools in kindergarten, 2nd, 6th, and 9th grade shall have a dental examination (105 ILCS 5/27-8.1(2)); and
  - Children enrolled in public, private, and parochial schools in kindergarten shall have an eye examination (105 ILCS 5/27-8.1(3)).

- The School-Based/Linked Health Centers Code (77 Ill. Admin. 641) sets forth the standards for certification of school- based health centers in Illinois. The purpose of school health centers is to “improve the overall physical and emotional health of students by promoting healthy lifestyles and by providing available and accessible preventive health care when it is needed.”

- The Maternal and Child Health Services Code (77 Ill. Admin. Code 630) makes the planning, programming, and budgeting for MCH programs the responsibility of IDPH and requires IDPH to give the University of Illinois, Division of Specialized Care for Children “at least the amount of federal Maternal and Child Health Services Block Grant funds required by Title V” for services for children with special health care needs. It also authorizes IDPH to award funds for programs providing health services for women of reproductive age, programs providing health services for infants in the first year of life, health services for children from one year of age to early adolescence, and programs providing health services for adolescents.

- The Public Water Supply Regulation Act (415 ILCS 40/7a) requires the “owners or official custodians of public water supplies” to follow the recommendations on optimal fluoridation for community water levels as a means of protecting the dental health of all citizens, especially children.

- The Child Hearing and Vision Test Act (410 ILCS 205) requires children to be screened for vision and hearing problems as early as possible, but no later than their first year in any public or private education program, licensed day care center, or residential facility for children with disabilities. It also requires periodic screening thereafter.

- The Lead Poisoning Prevention Act (410 ILCS 45) requires physicians and health care
providers who see or treat children 6 years of age or younger to test children for lead poisoning when they live in an area defined as high risk by IDPH.

- The Substance Use Disorder Act (20 ILCS 301) requires:
  - Establishment and support of programs and services for the promotion of maternal and child health; Establishment of substance abuse prevention programs; and
  - The creation of a list of all providers licensed to provide substance use disorder treatment to pregnant women in Illinois.

- The Suicide Prevention, Education, and Treatment Act (410 ILCS 53) authorizes IDPH to carry out the Illinois Suicide Prevention Strategic Plan and to fund up to five pilot programs that provide training and direct service programs relating to youth, elderly, special populations, high-risk populations, and professional caregivers.

- Section 17 of the Children and Family Services Act (20 ILCS 505) requires the development of the Comprehensive Community Based Youth Services program to ensure that youth who do or may interact with the child welfare and juvenile justice systems have access to needed community, prevention, diversion, emergency, and independent living services.

- Section 16.1 of the Probation and Probation Officers Act (730 ILCS 110) authorizes the Redeploy Illinois program, which is intended to encourage the deinstitutionalization of juvenile offenders and offer alternatives, when appropriate, to avoid commitment to the Department of Juvenile Justice.

- The Juvenile Court Act of 1987 (705 ILCS 405) establishes juvenile probation services with the goal of allowing youth to remain with their families whenever possible to maintain the youth’s moral, emotional, mental, and physical welfare.

- The Emancipation of Minors Act (750 ILCS 30) allows homeless minors to be emancipated from their parents.

- The Specialized Care for Children Act (110 ILCS 345) designates the University of Illinois Division of Specialized Care for Children as the agency to administer federal funds to support Children and Youth with Special Health Care Needs (CYSHCN).

- The Illinois Domestic Violence Act of 1986 (750 ILCS 60) defines abuse, domestic violence, harassment, neglect, and other terms, and authorizes the issuance of orders of protection. The Domestic Violence Shelters Act (20 ILCS 1310) requires the Department of Human Services to administer domestic violence shelters and service programs.

- The Reduction of Racial and Ethnic Disparities Act (410 ILCS 100) requires IDPH to establish and administer a grant program to "stimulate the development of community-based and neighborhood-based projects that will improve the health outcomes of racial and ethnic populations" And was envisioned to "function as a partnership between State and local governments, faith-based organizations, and private-sector health care providers, including managed care, voluntary health care resources, social service providers, and nontraditional partners."

- The Reproductive Health Act (IL Public Act 101-0013) sets forth “the fundamental rights of individuals to make autonomous decisions about one’s own reproductive health, including the fundamental right to use or refuse reproductive health care.”

- Task Force on Infant and Maternal Mortality Among African Americans Act (IL Public Act 101-0038) created a task force establishing best practices to decrease infant and maternal mortality among African Americans in Illinois and produce an annual report to the General Assembly detailing its findings and recommendations.
• Maternal Blood Pressure Equipment Act (IL Public Act 101-0091) requires hospitals to have proper instruments available for taking a pregnant woman’s blood pressure.

• Maternal Mental Health Insurance Coverage Act (IL Public Act 101-0386) requires insurance coverage for mental health conditions that occur during pregnancy or during the postpartum period.

• Hospital Hemorrhage Training Act (IL Public Act 101-0390) requires all birthing facilities to conduct annual continuing education that includes management of severe maternal hypertension and obstetric hemorrhage.

• Pregnancy and Childbirth Rights Act (IL Public Act 101-0445), amends the Medical Patient Rights Act by setting forth certain rights that women have with regard to pregnancy and childbirth, which include appropriate access to care prior to, during and after the pregnancy, choice in the type of provider for her maternity care professional and the setting in which she receives her care. Healthcare providers, including hospitals, are required to post information about these rights in a prominent place in their facilities and on their websites.

• Reporting of Infant and Maternal Mortality Act (IL Public Act 101-0446) provides changes to the Hospital Report Card Act by requiring hospitals to submit as part of their quarterly reports to IDPH: Each instance of preterm birth and infant mortality within the reporting period, including the racial and ethnic information of the mothers of those infants; and Each instance of maternal mortality within the reporting period, including the racial and ethnic information of those mothers.

• Maternal Levels of Care Act (IL Public Act 101-0447) requires IDPH to establish levels of maternal care for hospitals in Illinois. These levels of care are to be complimentary but distinct from the perinatal levels of care system. IDPH, by rule, will develop criteria for the designation of hospitals based on their capabilities. The department will also collect additional data on maternal mortality and morbidity to lead any future changes to the maternal levels of care.

• Maternal Mental Health Education Act (PA 101-0512) creates the Maternal Mental Health Conditions Education, Early Diagnosis, and Treatment Act which requires the Department of Human Services (DHS) to develop educational materials on maternal mental health conditions and make them available to birthing hospitals. Starting Jan. 1, 2021, applicable hospitals must distribute those materials to employees regularly working with pregnant or postpartum women, as well as supplement the materials with information and resources relevant to their facility or region.
III.C. Five-Years Needs Assessment

III.C.2.a. Process
Illinois’s 2020 Needs Assessment (NA) was conducted by the IL Title V (IDPH and UIC-DSCC), in collaboration with UIC School of Public Health’s Center of Excellence in Maternal and Child Health (CoE-MCH) through a long-standing intergovernmental agreement to enhance MCH epidemiologic capacity.

The complexity and magnitude of current MCH challenges require innovative and collaborative solutions. The IL Title V strives to be the “convener” of statewide MCH activities, bringing together key stakeholders to create a shared understanding of IL MCH needs and priorities, as well as promising strategies to address them. The intent of the robust IL Title V NA process was to inform Title V prioritization for the next five years (2021-2025) and generate an Action Plan to serve as the framework through which MCH activities in IL are aligned, duplication of efforts is reduced, and synergy amongst partners is centralized.

The NA team at the CoE-MCH included MCH and MCH Epidemiology faculty, public health students, and other researchers. The team established a NA activity timeline in August 2018 and held bi-monthly meetings thereafter.

The IL NA framework included:
1. Assessment of health status, service needs, and system capacity related to each population domain
2. Development of 2021-2025 priorities
3. Assessment of workforce and agency capacity
4. Development of strategies and a final Action Plan

The IL Title V NA team challenged themselves to identify new methods to engage both professional and consumer stakeholders. The process required extensive collection and analysis of primary and secondary data from a variety of sources; a concerted effort was made to collect more qualitative data than in the past to address gaps in knowledge. Stakeholders provided guidance and feedback throughout the NA.

The mechanisms for gathering stakeholder input included:

- **An Expert Panel (EP)**, with a nested **Advisory Council (AC)**, of professional stakeholders was established to solicit feedback on the state’s MCH needs, priority selection, and strategy identification and to advise the overall process.
- **Key Informant Interviews** with IL Title V Leadership and staff were conducted to assess capacity and describe needs within in their programs.
- **Consumer Listening Sessions including members** of the Illinois MCH Family Council and School-Based Health Centers’ Youth Advisory Councils were convened to identify emerging trends.
- **Surveys** were designed and deployed to determine workforce capacity, to assess partners’ views of Illinois Title V capacity, and to gather consumer stakeholder input.

Additionally, several products were developed for stakeholder consumption to increase knowledge about MCH health status and needs. The collaborative NA process spanned 22 months, allowing time for critical team reflection and modifications based on stakeholder feedback (Figure 1).
Figure 1: Illinois Title V NA Process for 2021-2025

1. Develop Data Sheets to Review Baseline Data
   - Gathered and analyzed data (e.g., NPMs) and qualitative data from listening session with the Illinois MCH Family Council members.

2. Advisory Council Meeting #1
   - Convened a small group of stakeholders; provided overview of Title V and Needs Assessment process, discussed emerging topics, reviewed data sheets, and identified additional data needs.

3. Gather Additional Qualitative Data on Children
   - Conducted key informant interviews with School Health Program staff, listened to sessions with youth advisory councils at School-Based Health Centers, and surveyed UIUC-DSSC Families.

4. Advisory Council Meeting #2
   - Discussed impressions of data, reviewed relevance of 2015-2020 priorities, and identified additional data needs.

5. Synthesize and Incorporate Feedback on Priorities from Advisory Council
   - Gathered feedback (keep, change, remove, add) from Advisory Council on 2015-2020 priorities.
   - Solicited comments from Advisory Council on proposed 2021-2025 priorities.

6. Generate 2021-2025 Priorities
   - Using analyses of current health status and feedback from Advisory Council, proposed new priorities for 2021-2025 grant cycle.

7. Agency Capacity and Budget Assessment
   - Key informant interview with IDPH Title V leadership to evaluate agency capacity and budget in the context of developing new strategies that address priorities.

8. Workforce Capacity Assessment
   - Administered survey for IL Title V Staff (IDPH and UIUC-DSSC) to identify workforce and training needs.

9. Public (Consumer) Input
   - Developed and deployed a public input survey on social media to identify MCH Issues and ensure alignment between proposed priorities and consumer needs.

10. Expert Panel Webinars
    - Recruited larger group of stakeholders; hosted a total of 4 webinars (2 aimed at women/maternity/infant and 2 aimed at children/CYSCHN/adolescents) to review proposed 2021-2025 priorities and identify strategies.

11. Expert Panel Feedback
    - Gathered feedback via email on drafted Action Plan.

12. Partner Assessment
    - Administered survey for key IL Title V Partners to identify training needs, assess quality of partnerships, and identify areas for improvement.

    - Synthesized feedback and capacity assessments and developed 2021-2025 Action Plan.

14. Public Comment

Steps in IL Needs Assessment:
1. Assessment of health needs in each population
2. Development of 2021-2025 priorities
3. Assessment of workforce and agency capacity
4. Development of strategies and final Action Plan
Step One: Assessment of Health Needs in Each Population Domain

Datasheets

The NA team provided information on several MCH indicators before professional stakeholder conversations began. The intent was to frame conversations and give context to the work of the IL Title V. The NA team created “datasheets” for each population domain using state and national performance and outcome measures (Appendix A). For each measure, the most current data available for Illinois, the average annual percent change over the last five years, Illinois’ national rank, and an indicator of racial/ethnic disparity were presented. The measure of disparity was included because health equity is a priority for IL Title V and an area of concern continually voiced by partners.

Qualitative data from the Illinois MCH Family Council and Youth Advisory Councils (described in the next sections) were also included on the datasheets, adding depth and illuminating community and family contexts for the quantitative measures. The datasheets successfully framed subsequent conversations during Advisory Council and Expert Panel meetings and helped to make these discussions richer and data-informed. Participants referred to the datasheets to reiterate the importance of health conditions for a particular population, and to support their decision-making about keeping, changing, or deleting the 2016-2020 IL Title V Priorities.

Illinois MCH Databook

The datasheets served as the foundation for a larger data resource, the Illinois MCH Databook 2020 (Appendix B). The Databook was an iterative project spanning the length of the NA; the creation of the Databook was both informed by the NA process and aided in the development of state priorities and the Action Plan. The NA team included measures they believed best described the highest needs and priorities for Illinois as well as additional measures of importance identified at the AC meetings.

Measures are organized by population domain and presented individually or in combination with related measures. A separate section presents cross domain measures that may be considered together to give a population or life course perspective (e.g., substance abuse and mental health disorders). The measure pages are designed to stand alone and can be shared as separate documents if a partner or community member requests information on a single measure.

Methods for the Databook were selected and designed to communicate the most salient information about each health measure. A statewide average, and results stratified by geography, race/ethnicity, insurance status, sexuality, and/or age are presented. If available, state trends over time are also provided. Data source, definition, interpretation of results, and suggested evidence-based action steps partners may take to address the health measure are also included. In a large and geographically diverse state such as Illinois, MCH outcomes often vary by geographic area. Thus, several measures, such as adequacy of prenatal care, are presented in a map format, with results shown at the county level.


IDPH/EverThrive Illinois MCH Family Council Listening Sessions

Voices of individuals and families who benefit most directly from Title V funding, programming and policy
drove the development of many NA activities. The first solicitation of public input to assess need occurred from December 2018-March 2019: the NA team facilitated semi-structured listening sessions with active members of the IDPH/EverThrive Illinois MCH Family Council convened in six regions: South Side Chicago, West Side Chicago, Edwardsville, Marion, Rockford and West Chicago. Participants shared their frank assessments of 1) positive and negative aspects of their communities; 2) health concerns specific to each Title V population domain; and 3) current Title V priorities. Participants gave verbal consent to be recorded anonymously. There was a total of 20 participants (19 women, 1 man; age range of 18-54 years; 11 Black, 2 Latinx, 5 White and 2 ‘other’). Most had children who were Medicaid recipients, and more than half were Medicaid recipients themselves. Recordings were transcribed, imported into the qualitative analysis software Dedoose Version 8.3.17, and analyzed for emergent themes. Thematic findings were integrated into the datasheets to further illustrate the quantitative data. Findings were also shared back with members to validate the NA team’s interpretations of data.

Advisory Council (AC)

In early 2019, a group of external professional stakeholders (n=12) with ties to the IL Title V or MCH efforts in IL were invited to participate in an AC, with 2-3 stakeholders per population domain. This group was charged with providing commentary on current MCH status, feedback on the 2016-2020 priorities, and advising on additional data needs or changes to the NA process.

A joint webinar and in-person meeting were held in April 2019 to engage the AC and facilitate a discussion on the status of MCH in IL. Datasheets were distributed ahead of time and were referenced throughout the presentation. Discussion topics included whether the data presented were consistent with AC members’ experience and if there were noticeable gaps in data that should be addressed by Title V. This meeting was well attended but participation was less robust than anticipated.

In May 2019, the NA team discussed ways to improve AC engagement. An assignment was developed to elicit additional feedback on surprising findings from the datasheets as well as thoughts on additions, revisions and deletions to the 2016-2020 priorities. There was a good response and this additional feedback was incorporated into materials for the second AC meeting in July 2019, which was very productive.

Youth Advisory Councils Listening Sessions

Given the unique physical and socio-emotional health needs of adolescents, the NA team wanted to directly involve young people to gain their perspectives. To prepare for this activity, NA team members convened a semi-structured discussion in January 2019 with the IDPH School Health Program (SHP), including the program administrator and three nurse consultants. This planning discussion considered requests for technical assistance received from school health centers, along with ‘hot topics’/health concerns raised by the school health centers’ Youth Advisory Councils (YACs). Findings were used to develop an interview guide for subsequent listening sessions with the YACs.

IDPH SHP staff assisted in selecting School-based Health Centers (SBHC) to host listening sessions in a total of six locations: 4 public high schools in Chicago and 1 high school and 1 middle school in Peoria were chosen. In April 2019, members of each YAC received a short questionnaire including socio-demographic and open-ended questions. Students reflected on positive and negative aspects of the communities in which they lived as well as their main health and social concerns as young people. The NA team used these responses to facilitate semi-structured conversations with YAC members and key informant interviews with YAC advisors (staff members of community-based organizations) at each selected site in May 2019. A total of 40 students, females and males aged 12-18, participated in the six sessions. Session notes were imported into the qualitative analysis software Dedoose Version 8.3.17 and analyzed for emergent themes. Findings were integrated into the datasheets to further illustrate relevant
quantitative data on statewide MCH outcomes. Results were also shared with pertinent partners via a public-facing document published and distributed by IDPH (Appendix C).

**Pregnancy Risk Assessment Monitoring System (PRAMS)**

The NAS team conducted a qualitative analysis of the 2016-2017 IL PRAMS “back page” open-ended prompt: “Please use this space for any additional comments you would like to make about your experiences around the time of your pregnancy or the health of mothers and babies in Illinois.” Comments were imported into Dedoose Version 8.3.17 and analyzed for emergent themes. Identifying themes related to social determinants of health and healthcare access and quality was emphasized. Of the 2,606 respondents, 14.8% (n= 386) provided comments and about half (n=197) were tagged with at least one theme relevant to the NA. Overall, n=45 themes were identified.

**UIC-DSCC Parent Survey**

UIC-DSCC conducted a 2019 Family Survey to capture input on experiences of Illinois families enrolled in UIC-DSCC care coordination programs focused on the six core outcomes for CYSHCN systems. The survey questions were constructed using the National Survey for Children’s Health (NSCH) to allow UIC-DSCC to compare its results to those of the National Survey results. The Family Survey also included open ended comments to capture additional input from the respondents. The Family Survey was launched in April 2019. A total of 5,248 families were sent the survey, 2,927 families with known email addresses received a survey link and another 2,321 families were mailed the survey. Two reminder postcards were mailed, and the survey closed May 31, 2019. Individuals not eligible to participate in the surveys were youth in care where the family spoke a language other than English or Spanish, and youth in care that would be 18 years old by the time the survey period closed. A total of 1,005 survey responses were received (19% response rate) which provided a sampling error of ±2.4% at the 95% confidence interval. Black or African American and Hispanic children and youth, and children under the age of 6 were under-represented in the survey. Pearson chi-square tests were used for statistical analysis.

Survey results were compared to the NSCH on the following outcomes: (1) Families of CSHCN partner in decision-making regarding their child’s health; (2) CSHCN receiving coordinated and ongoing comprehensive care within a medical home; (3) Community-based services are organized so families can easily access them; (3) Families of CSHCN have adequate private and/or public insurance to pay for needed services; and (4) Youth with special healthcare needs receive the services necessary to make transitions to adult health care. It should be noted that the comparisons were made to the NSCH results for Illinois who met the criteria as “more complex” in an attempt to make the data more comparable.

**UIC-DSCC Program Staff Key Informant Interviews**

UIC-DSCC’s care coordination team and program leadership are positioned across the state. Given the local relationships with medical and community groups serving CYSHCN along with direct interaction with over 7,000 UIC-DSCC Program participants and their caregivers, UIC-DSCC gained perspectives from team members. Semi-structured interviews were held in November and December 2019 and included participation from DSCC care coordination leadership team and selected team members from the quality improvement teams. During the interviews, the participants discussed areas of need and opportunity pertaining to systems of care and support for CYSHCN across the state.

**Step Two: Development of Priorities for 2021-2025**

**Advisory Council Involvement**
After the July 2019 meeting, AC members were asked to finalize their positions on keeping, revising or removing each of the 2016-2020 priorities. The discussion was guided by the following questions:

- Which areas of the 2016-2020 IL Title V Action Plan are robust? Which could be strengthened?
- Where is there flexibility in funding for new efforts?
- Are there current efforts that could be better highlighted and possibly expanded?
- For the new areas proposed by the AC, are there staff and capacity to adequately address?

Reflecting on the 2016-2020 priorities, it was determined that IDPH should conceptually change how it integrated health equity and consumer engagement in its priorities. During 2016-2020, there were two specific cross-cutting priorities set forth: (1) Assure that equity is the foundation of all MCH decision-making; and (2) partner with consumers, families and communities in decision-making across MCH programs, systems and policies. It was agreed that since health equity and consumer engagement were pillar activities relevant to all future Title V efforts and initiatives, they would be promoted to overarching principles for all priorities, rather than individual priorities of their own. During the July AC meeting, this proposal was validated. The AC recommended adding a priority for maternal and postpartum health, broadening the child focused priority from 2016-2020, and including system-level language in the adolescent priority.

Similar to IDPH’s approach, UIC-DSCC reviewed it’s two priorities from 2016-2020 to determine if they could be strengthened, to see if they aligned with the data from the needs assessment, and if they provided opportunity for UIC-DSCC to expand its efforts beyond the care coordination services it currently provides. It was determined that efforts to prepare CYSHCN for the transition to adulthood, a current priority, could be strengthened and the second priority which focused on enhancing the capacity of families to connect CYSHCN to the health and human services required for optimal behavioral, developmental, health, and wellness outcomes could be eliminated. Justification for the elimination of the second priority was because it was embedded in current care coordination practices across the state. UIC-DSCC developed a new priority.

Illinois Title V leadership drafted their population domain and cross-cutting priorities to proceed with a final set of 10 proposed 2021-2025 priorities for AC approval. Email communication with the AC during December 2019 generated overwhelmingly positive feedback on the proposed 2021-2025 priorities. The Illinois Title V Priorities for FY 2021-2025 are as follows:

**Domain: Women/Maternal Health**
1. Assure accessibility, availability, and quality of preventive and primary care for all women, particularly for women of reproductive age. *(Repeat Priority)*
2. Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum. *(New Priority)*

**Domain: Perinatal/Infant Health**
3. Support healthy pregnancies to improve birth and infant outcomes. *(Repeat Priority)*

**Domain: Child Health**
4. Strengthen families and communities to assure safe and healthy environments for children of all ages and enhance their abilities to live, play, learn, and grow. *(New Priority)*

**Domain: Adolescent Health**
5. Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors. *(Revised Priority)*
**Domain: Children and Youth with Special Health Care Needs**

6. Strengthen transition planning and services for children and youth with special health care needs. *(Revised Priority)*

7. Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs. *(New Priority)*

**Domain: Cross Cutting**

8. Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders. *(Repeat Priority)*

9. Support an intergenerational and life course approach to oral health promotion and prevention. *(New Priority)*

10. Strengthen the MCH epidemiology capacity and data systems. *(Revised Priority)*

**Listening Session with MCH Family Council Members**

A subset of MCH Family Council members (n=6) who attended the Illinois Women and Families Health Conference in October 2019 and were asked to participate in a review of the previously conducted listening session results and the new proposed priorities. Following a presentation of the themes and findings (Appendix D), participants engaged in a robust discussion confirming the identified needs and priorities. They also highlighted additional areas of concern.

**Step Three: Assessment of Workforce and Agency Capacity**

**Agency Capacity and Budget Assessment**

In spring 2019, the CoE-MCH NA team conducted a key informant interview with IDPH-MCH Title V Leadership (OWFHS Deputy Director and interim IDPH-MCH Title V Director) to explore the relationship between the IL Title V budget, staffing, and program capacity. Specifically, the conversation focused on the availability of state ‘matched’ revenue, Title-V funded staff positions, and key positions needed to enhance infrastructure (e.g., Title V Block Grant coordinator). Following this interview, the interim IDPH-MCH Title V Director reached out to the directors of other large states for organizational charts to understand the ways in which Illinois’ Title V staffing could be expanded.

**Workforce Survey**

The NA team administered a Workforce Survey to Title V staff in March 2020 via REDCap. The survey captures characteristics of the two Title V workforces and identifies training needs (Appendix E). The DSCC workforce contains over 225 individuals and the IDPH-MCH workforce included 18 staff members (13 Title V funded staff and 5 IDPH OWHFS staff who provide in part leadership, grant or fiscal support).

**Partner Survey**

In March 2020, a survey was developed inviting partners to reflect on their specific relationships with the IL Title V (Appendix F). The IL Title V Director invited external members of the NA Expert Panel (n=71) to take this 15-minute online survey via REDCap. The survey assessed: 1) partners’ perspectives of their relationships with Title V; 2) intentions for future relationships; 3) perceptions of IL Title V functioning; 4) technical assistance needs; and, 5) general feedback about IL Title V. The survey was completed by 36/71 (50.7%) invitees.

**Step Four: Development of Strategies and Final Action Plan**
Expert Panel Webinars

To gather broad, diverse input on potential strategies to address the 2021-2025 priorities, the NA team and IDPH convened an Expert Panel (EP) consisting of professional stakeholders representing public health practitioners, medical care providers, academics, researchers, administrators, and advocates from the private and public sectors. IL Title V invited 106 leaders from organizations in the MCH field across Illinois to join, and 67% participated (n=71). A series of four interactive webinars facilitated by NA team members were planned for January 2020. Two webinars focused on priorities related to children, CYSHCN, and adolescents and two focused on reproductive aged women, pregnant women, and infants. All webinars addressed the crosscutting/life course priorities of mental health, substance use/misuse, oral health, and data capacity (Figure 2). Webinar discussions began with panel members taking a poll to identify how well their work aligned with each of the Title V priorities. Discussions were guided by members’ perspectives on what was being done that was working well, ideas about new and creative approaches, and suggestions for what others might be able to do to support their respective work, particularly the IL Title V.

The interactive nature of the webinars created a synergy among participants, facilitating a rich discussion about the significance of the Title V priorities and opportunities for collaboration. EP input was captured through webinar recordings, chat messages, and a follow-up feedback form netting ‘afterthoughts’ stimulated by the group discussion. Input was summarized by priority and organized by key issues, opportunities for collaboration, and potential strategies. Draft summaries (Appendix G) were sent to participants for review and comment.

Public Input/Consumer Survey

A public input survey was deployed via the internet to identify MCH issues and ensure alignment between the proposed 2021-2025 priorities and consumer needs (Appendix H). Open-ended questions asked about important health concerns, problems, or challenges by population domain and for respondents’ communities overall. Questions also focused on barriers and discrimination experienced when accessing or receiving healthcare or other services. Four questions about home visiting services assisted the IL MIECHV program in their tandem NA. The survey was created in SurveyMonkey and was available in English and Spanish. IL Title V leadership created posts on Facebook and Twitter, and sent emails to UIC-DSCC, the MIECHV program, and AC members with information on how to share the links. The survey was open for two months and analysis was limited to those living in IL. There was a total of 553 responses (97% women; 82% White, 9% Latinx/Hispanic, 5% Black, 4% other including Asian; 22% Medicaid recipients).

Develop Final Action Plan - For IDPH to complete after public comment period ....

Solicit Feedback from Expert Panel on Action Plan – On August XX, all expert panelist were sent a copy of the proposed Action Plan (2021-2025) along with the draft Title V Application for review and feedback. For IDPH to complete after the comment period...

Public Input/Posting of Block Grant for Feedback - For IDPH to complete after public comment period...

III.C.2.b. Findings

III.C.2.b.i. MCH Population Health Status
Emergent Consumer Stakeholder Themes across Population Domains

Consumer stakeholders identified multiple barriers to accessing affordable, high quality and timely health care well-adapted to the needs of consumers (physical and developmental disabilities and delays, communication barriers and trauma-informed care). Barriers included the prohibitive cost of private health insurance and services including life-saving medications; inadequate coverage provided through private and public insurance including exclusion of ‘complementary treatments’ (e.g. chiropractic); inadequate number of providers who accept Medicaid, especially specialists and in rural areas; lack of paid parental leave and its effect on family bonding and attendance at child and women’s health appointments; and time-consuming navigation of health and social service systems resulting in delays in care and coverage.

Consumer stakeholders described one or multiple forms of discrimination experienced when seeking care (Table 1). Women especially felt ‘unheard’ about their own health and ‘bullied’ into accepting medical intervention specifically during childbirth; a number of consumers said their concerns as patients and parents were not addressed.

Table 1. Forms of discrimination experienced by consumer stakeholders

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender identity</th>
<th>Race &amp; Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual orientation</td>
<td>Immigration status</td>
<td>Disability</td>
</tr>
<tr>
<td>Marital status</td>
<td>Religion</td>
<td>Incarceration</td>
</tr>
<tr>
<td>Language</td>
<td>Weight</td>
<td>Military status</td>
</tr>
<tr>
<td>Medicaid status</td>
<td>Refusal of medical procedures</td>
<td>Homebirth</td>
</tr>
<tr>
<td>Substance use disorder</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mental health services throughout the life course were reported by consumers to be severely lacking, especially for those on Medicaid. There is also a perception that there has been an increase in non-communicable/chronic disease and substance use disorder across populations. Health education about numerous topics was also proposed as a need (Table 2).

Table 2. Health education topics proposed by consumer stakeholders

<table>
<thead>
<tr>
<th>Health literacy</th>
<th>Hygiene</th>
<th>Disease prevention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>Life skills</td>
<td>Maternal health</td>
</tr>
<tr>
<td>Parenting, child development</td>
<td>Healthy relationships</td>
<td>Preventive care</td>
</tr>
<tr>
<td>Reproductive health</td>
<td>Safe Sleep</td>
<td>Vaccination importance</td>
</tr>
</tbody>
</table>

Social Determinants of Health

Consumer stakeholders highlighted a number of social determinants of health affecting their physical and emotional wellbeing. Specifically, consumers listed limited access to nutritious food, affordable, quality housing, high performing schools, safe neighborhoods and reliable transportation. A lack of paid maternity, sick and/or family leave and few affordable, quality childcare options also contributed to a number of poor health outcomes. Inaccessible, unaffordable, and inadequate spaces for safe, interactive play was linked to perceived increases in obesity, social isolation, and neighborhood violence.

Women’s/Maternal Health

Qualitative themes pertaining to women’s and maternal health identified across all consumer stakeholder groups (MCH Family Council, Public Input, PRAMS) included: poor provider availability and accessibility; poor mental health and need for community supports; need for high quality, respectful care and support during pregnancy; importance of timely prenatal care (PNC); postpartum stress and wellbeing; and parenting support. Additional themes raised by at least one of the consumer stakeholder groups covered: gender discrimination and inadequate trauma informed care; need for affordable/free contraception,
abortion services, and sexually transmitted infection (STI) testing; need for increased screening for chronic disease and disabilities for women; inconsistent Medicaid coverage and administrative requirements; need for enhanced outreach and support services for women experiencing intimate partner violence; need for access to care for high risk pregnancies; need for licensure of certified practicing midwives (CPM); need for increased insurance coverage for doulas, lactation consultants, CPM’s and birth centers; excessive obstetric interventions (inductions, C-sections, episiotomies); negative experiences during PNC and childbirth, including a sense of bullying and obstetric abuse; impact of maternal stress, anxiety, and mental health status on child wellbeing; difficulties balancing multiple roles and self-care along with parenting after childbirth; and unaffordable quality child care and inadequate early childhood education.

The quantitative findings highlighted the burden and disparities in chronic disease, mental health disorders and maternal morbidity and mortality for IL women. Among women of reproductive age in 2018, 2.4% had chronic diabetes, 9.8% had chronic hypertension, and 11.2% had asthma. Half of women were overweight or obese (54%), with Black women and women in rural counties experiencing particularly high rates, at 76% and 65% respectively. In 2017, about 14% of women ages 18-44 smoked, but the prevalence reached over 30% among women in rural counties. STIs are of particular concern for young women in IL. In 2018, the rate of Chlamydia infection among women ages 15-24 was over 430 cases per 10,000 women and was more than five times higher among Black compared to White women. STI rates were highest in the city of Chicago and in urban counties outside the Chicago metropolitan area. While receipt of an annual check-up has improved over time, in 2018, 25% of women ages 18-44 reported no visit, and only 80% reported having a personal healthcare provider.

In 2018, in six women ages 18-44 reported poor mental health during the last month. Mental health conditions were also the leading cause of hospitalization for women ages 15-44 after hospitalizations for delivery. Intimate partner violence may contribute to mental health issues. About 2.3% of Illinois women delivering a baby in 2017 reported physical abuse by their husband/partner in the year before pregnancy.

In 2018, 24% of Illinois women received less than adequate prenatal care, most commonly in Chicago (33%), among Black (39%) and Hispanic (29%) women and teen mothers (38%). Stark racial disparities characterize maternal morbidity and mortality in IL. The rate of severe maternal mortality (SMM) was 51 per 10,000 deliveries (2016-2017, excluding transfusions) and was almost three times higher for Black compared to White women. In 2015-16, there were 61 pregnancy-related deaths, a ratio of over 19 deaths per 100,000 live births, of which 66% were determined to be potentially preventable. This ratio was over six times higher among Black compared to White women. The leading cause of death for pregnancy associated and pregnancy related deaths was mental health issues, inclusive of substance use disorders.

**Perinatal/Infant Health**
Qualitative themes identified across consumer stakeholder groups (MCH Family Council, Public Input) pertaining to the perinatal and infant health domain included: issues and concerns related to successful breastfeeding (BF), such as medication use, adequate milk production, inadequate BF supports in the hospital, at home and at work, high cost of pumping equipment, and pressure to BF; insufficient WIC formula allowance and high cost of formula; perception of excessive infant mortality and morbidity; and increased support for needs of premature infants and their families.

The concerns related to infant mortality are supported by quantitative data showing level infant, neonatal and post-neonatal mortality rates over the last 8 years and persistent disparities in birth outcomes by race/ethnicity. There were 6.5 infant deaths per 1,000 live births in 2016-2018; infants born to Black compared to White women were 2.9 times as likely to die in the first year of life. Disparities in post-neonatal mortality rates, particularly due to Sudden Unexplained Infant Death (SUID), are even more
striking and have widened over time; Black-White ratios for post-neonatal death and SUID were 4.2 and 4.8, respectively, in 2016-2018.

The rate of the leading cause of infant mortality, preterm birth, increased to 10.7% in 2018, well above the Healthy People 2020 target of 6.8%; the Black-White ratio was 1.6. While IL saw early gains in reducing non-medically indicated early deliveries (NMIED), the NMIED rate then increased from 9.4% of term births in 2014 to 12.3% in 2018. In 2018 in IL, 82.3% of VLBW infants were born in a Level III+ perinatal hospital with a neonatal intensive care unit, up from 77.6% in 2010. However, women residing in rural counties lag behind on this indicator, at 71.9%.

While some consumer stakeholders described challenges initiating BF, statistics from 2013-2017 show overall improvement in rates of BF initiation (88.2%, 2017) and BF to twelve weeks (61%, 2017). Women across all demographic subgroups met or exceeded the Healthy People 2020 objective of 81.9% for BF initiation and IL has seen a steep increase in the proportion of infants born in Baby Friendly hospitals (from 2.2% in 2014 to 20.6% in 2018). However, lower rates of exclusive BF to 12 weeks (34%, 2017) support the reports from consumer stakeholder’s about difficulties sustaining BF. Black mothers and young mothers are in particular need of support for longer duration of exclusive BF.

**Child Health**

Qualitative themes identified across consumer stakeholder groups (MCH Family Council, Public Input) regarding child health included: need for care coordination across different Managed Care Organizations (MCO)s; need for enhanced and affordable mental health services and timely trauma screening and trauma informed services; excessive use of technology/screen time and relationship to obesity and developmental delays; need for developmental and behavioral health assessments and services, including quality screening, treatment, and enhanced education and training for teachers; geographic inequity in environmental exposures (air pollution, lead) and impact on child health. Both consumer stakeholder groups noted the importance of prevention, screening and treatment for chronic diseases; asthma was noted as particularly challenging due to environmental exposures and a sense that it is not taken seriously by many providers.

While 79% of IL children ages 0-17 had at least one well child visit in the last year, consumer stakeholder concerns about fragmented care are supported by quantitative data; only half of IL children received care that met all the requirements of a medical home in 2016-2018. Racial/ethnic and income-based disparities exist, with minority children and those from poor or near poor families being less likely to have a medical home. Some consumers voiced concerns over the perceived increase in unvaccinated children; however, this is an area of improvement in IL. The percent of toddlers (19-35 months) fully immunized with the 4:3:1:3:3:4 series (DTap, Polio, MMR, Hib, HepB, Varicella, Pneumococcal) increased from 53.7% in 2009 to 75.4% in 2017, on track to possibly meet the Healthy People 2020 objective of 80%.

Chronic conditions are common among IL children, as indicated by the consumer stakeholder groups. In 2016-2018, 9% of children were reported to have current asthma and the rate of pediatric emergency department (ED) visits for asthma was 71 per 10,000 children; for Black children, the prevalence was 19% and the ED visit rate exceeded 200 per 10,000. Childhood obesity is also prevalent with 29% of 10-17-year olds obese and 41% of children from low income families. Over 17% of IL children suffered from a mental health condition in 2016-2018, of which anxiety was the most prevalent. The prevalence of mental health conditions is higher in children from low income families. While 13% of children in 2016-2018 had oral health problems, the prevalence was 17% for Hispanic children and was twice as high for children in low- or middle-income families compared to high income families. Almost 25% of children ages 1-17 did not have a preventive dental visit in the last year, a concern validated by consumer stakeholders.

Environmental and safe space concerns voiced by consumer stakeholders are echoed in the indicator data. Of IL children aged 1-5 years, 5.5% had elevated blood lead levels (≥5 µg/dL); about 11% of non-
Hispanic Black children had elevated blood lead levels compared to 6% of non-Hispanic White and 3% of Hispanic children. Unintentional injury remains the leading cause of death for children ages 0-14 in IL, with an overall rate of 1.7 per 100,000 and 3.9 per 100,000 in rural counties.

**Adolescent Health**

Qualitative themes identified across the consumer stakeholder groups (MCH Family Council, Public Input, YAC) related to adolescent health covered: need for comprehensive health education; available and affordable contraception; importance of formal and informal mentorship; bullying/cyber-bullying; poor mental health - depression and suicide; growing youth homelessness; increased support for Lesbian, Gay, Bisexual and Transgender and youth-friendly services and spaces; increasing SBHC’s; needs of undocumented youth; and the impact of neighborhood violence. Additional themes raised by at least one of the consumer stakeholder groups covered: increased awareness of the consequences of excessive screen time; importance of safe technology use; lack of physical activity; increases in non-communicable disease (diabetes, obesity); increase in substance use/misuse including vaping; importance of healthy relationships and consent; importance of STI prevention, testing and treatment; need for integration of oral health and primary care; and significance and value of peer educators.

Consumer stakeholders’ concern for adolescent mental health, including risk of suicide, is strongly supported by statistics. Suicide is the third leading cause of death for adolescents, increasing from 8.2 (2010) to 10.6 per 100,000 (2018); among youth aged 15-24, rates were highest in rural counties, among Whites and males. In 2017, 17% considered committing suicide and 10% attempted suicide in the last year. Bullying and cyber bullying, specific concerns of consumer stakeholders, are also prevalent: in 2017, 21% of high school students were bullied on school property and 17% were electronically bullied during the last month.

Violence is a major concern; homicide is the second leading cause of death for IL adolescents. In 2014-2018, the youth homicide rate was 22 deaths per 100,000. More than 3 of 4 youth homicide victims in IL were non-Hispanic Black. Dating violence is also a concern: among female students who dated, 11% experienced physical and 11% experienced sexual dating violence during the last year (2017).

While a decline was recorded from 2016 to 2018, unintentional injuries are still the leading cause of death among adolescents with the majority due to motor vehicle accidents (MVA). MVA-injury death rates among teens 15-19 were highest in rural counties in IL, among Whites, and among males. Consumer stakeholder concerns about adolescents using smartphones while driving are justified: in 2017, 37% of IL high school students who drove a car reported that they had texted while driving during the last year. Statistics also support consumer stakeholder concerns about teen substance use, though some improvements are promising: the percent of IL high school students who reported drinking alcohol decreased dramatically, from 44% in 2007 to 27% in 2017. About 19% of students reported tobacco use in the last 30 days and 13% reported vaping; both were higher among non-Hispanic White students and males. 1 in 5 IL high school students reported marijuana use in the last 30 days.

Consumer stakeholders were validated in prioritizing adolescents’ access to comprehensive sex education, STI testing/treatment and contraception. Although births to women ages 15-17 and 18-19 dropped by 62% and 47%, respectively, from 2010 to 2018, racial/ethnic and geographic disparities still exist. Black and Hispanic teens and those living in rural counties have higher teen birth rates. Condom use has significantly declined; in 2017, nearly half of sexually active students didn’t use a condom at their last sexual encounter.

Of IL high school students, over 86,000 (10%) identified as lesbian, gay or bisexual. This group reported a much higher prevalence of almost every adverse outcome examined compared to their heterosexual counterparts. Consumer stakeholders also cited this group as high risk and in particular need of extra resources and support to address mental health issues, suicide risk, sexual risk-taking, and substance
CYSHCN Health
Qualitative themes identified in both the UIC-DSCC Parent Survey and Public Input Survey included: a need for additional assistance preparing for the transition to adulthood; issues pertaining to insurance adequacy; caregiving challenges regarding ability to work and financial strain; and geographic impact on availability of services (medical, social, educational). Additional findings from the Public Input Survey included the need for more inclusivity, integration and adaption of services for CYSHCN and their caregivers.

Stakeholder interviews indicated a need for additional partnerships across communities pertaining to services needed by CYSHCN. This was reinforced in the expert panel reviews where recommendations included improved partnerships with other entities serving CYSHCN, a need for increased education and awareness of issues prevalent to Illinois CYSHCN, and suggestions to engage alternative providers such as Advanced Practice Nurses.

UIC-DSCC serves more than 16,000 children across the state of Illinois, representing 2.8% of the CYSHCN identified by the National Survey of Children’s Health (NSCH). Of those surveyed in the UIC-DSCC Parent Survey, 84.2% reported an increased need to access healthcare services, 75.8% reported functional limitations, and 79.5% require specialized therapies. According to the NSCH, nearly 1 in 5 children in Illinois were reported as having special healthcare needs. Approximately 64% of those identified children were reported to be in excellent or very good health. For children ages 3-17 years, approximately 4% were diagnosed on the autism spectrum, and nearly 10% were diagnosed with ADD/ADHD. Racial disparities were identified on all outcome measures as Black CYSHCN, on average, fared worse than other groups.

Preparation for the transition to adulthood remains a priority. In the UIC-DSCC Parent Survey, 11.4% of youth surveyed received transitional services which was lower than the 19.1% reported in the NSCH for the more complex Illinois population.

Adequate insurance is vital to improving and maintaining health. Only 54.9% of survey respondents reported adequate insurance. Families covered by private insurance or a combination of public and private insurance are more likely to have greater out of pocket expenses and hardships. According to the NSCH, the proportion of uninsured children in Illinois remains very low (4.7%); however, access to services remains an issue for this MCH population.

Respondents from the Parent Survey and the NSCH reported similar rates of receiving preventative care services, 70.8% and 71.7% respectively. As reported in the Parent Survey, only 40% of children received appropriate developmental screenings, and less than 20% of children were receiving care from a medical home. Medical Home use was reported at higher numbers by UIC-DSCC respondents at 44.2% than the NSCH respondents which reported at almost 35%. Respondents noted that two additional factors, geography and transportation, contributed to access challenges. An effort to alleviate these two contributing factors include offering such services within specific communities. Approximately 72% of Parent Survey respondents reported ease of access to community-based services compared to a little over 84% of NSCH respondents that reported ease of access. In addition, 86.3% of the respondents reported a partnership in decision-making regarding their child’s health, a higher percentage than reported by IL CYSHCN in the NSCH at 71.5%. When looking at the combined measure of family partnership, medical home, preventative care, adequate insurance, and transition assistance, it is evident that a need for improvement exists with receipt of services in a well-functioning system (UIC-DSCC 12.9% & IL CYSHCN NSCH 9.6%).

Systems
Overall, across all Title V 2021-2025 priorities, the work of EP members was predominantly “very aligned.” While EP webinar discussions focused on strategy development for each of the 2021-2025 priorities, participants also addressed these priorities with a system’s lens reflecting their individual and collective experiences. Leading systems issues identified included: fragmentation of services and need for comprehensive, coordinated, and integrated care; emphasis should be on best practice, quality, and timeliness of care rather than quantity; need for enhanced reimbursement and support for community based programs and services; scant primary care provider capacity; need for integrating a life course approach to health and wellbeing, getting beyond ‘health care’; need for the use of an inter-sectoral approach; more coordination of MCOs with other community programs and health care providers; and inadequate, timely, local data. Proposed strategies to address systems issues included youth, family, and community involvement in program development/implementation, use of social media, advisory groups, Medicaid policy change, and State Task Forces (Appendix G). Notably, many of these themes were also identified during the Listening Session with the MCH Family Council Members occurring in October 2019. Additional system issues discussed included experiencing a change in MCO provider without notification and being turned away at hospitals due to type of MCO provider.

III.C.2.b.ii IL Title V Capacity

III.C.2.b.ii.a. Organizational Structure

Illinois' Title V Maternal and Child Health Services Block Grant Program is administered by IDPH, Division of Maternal, Child, and Family Health Services (MCFHS) located in OWHFS. A subaward is given to the University of Illinois at Chicago Division of Specialized Care for Children (UIC-DSCC) to administer programming for CYSHCN.

OWHFS is one of six programmatic offices within IDPH. The vision of OWHFS is "a future free of health disparities, where all Illinoisans have access to continuous high-quality health care" and the mission is to “improve health outcomes of all Illinoisans by providing preventive education and services, increasing health care access, using data to ensure evidence-based practice and policy, and empowering families.” OWHFS houses three divisions: Division of Maternal, Child and Family Services, Division of Women's Health Services, and Division of Population Health Management. Together these divisions seek to support women's and family health across the lifespan.

UIC-DSCC is part of the University of Illinois at Chicago and reports to Office of the Vice Chancellor of Research. The Executive Director of UIC-DSCC is Thomas F. Jerkovitz. UIC-DSCC envisions that “children and youth with special healthcare needs and their families will be at the center of a seamless support system that improves the quality of their lives.” This vision is carried out by the mission to partner with Illinois families and communities to help children with special healthcare needs connect to the services and resources they need. An intergovernmental agreement formalizes the collaboration between IDPH and UIC-DSCC. UIC-DSCC is the sole recipient of funds for CYSHCN.

III.C.2.b.ii.b. Agency Capacity

IDPH

OWHFS is led by Shannon Lightner, MSW, MPA. Ms. Lightner served as the Deputy Director for 10 years. She has extensive MCH experience. She has previously worked at the American Cancer Society and served as a health policy advisor for two U.S. Senators and the Governor of Illinois.

Kenya D. McRae, JD, PHD, MPH, MBA, is Chief of the Division of Maternal, Child, and Family Health Services and the Title V Director. She oversees the operations of the Title V Block Grant, state MCH programs, and manages the Division Staff. She joined IDPH and the Title V staff in October 2019.
Illinois’ CDC Assignee in MCH epidemiology is Amanda Bennett, PhD, MPH. Dr. Bennett received her training in MCH epidemiology from the University of Illinois at Chicago, School of Public Health and joined IDPH in December 2014.

Although IL Title V workforce (n=18) is smaller than states with comparable population size, the program administers many initiatives and partners with a wide array of stakeholders to extend its reach across the state. Specific programs administered by the Title V staff include: a school-based health center program; adolescent health program to increase adolescent well-visits; administrative perinatal centers program that provides education, consulting and quality monitoring of Illinois’ birthing centers and hospitals; fetal and infant mortality review program; oral health programs with the IL Division of Oral Health; a maternal health program with the Department of Corrections; perinatal depression hotline; and a host of programs in collaboration with key stakeholders such as EverThrive Illinois, Illinois Perinatal Quality Collaborative, Illinois universities and colleges, Chicago Department of Public Health, and other local health departments. EverThrive Illinois plays an integral role in facilitating consumer engagement in IL Title V planning through the family councils established across the state. Additionally, Title V staff and programs convene and participate on various advisory councils to ensure it stays abreast of the needs of not only the MCH population, but also, the providers, organizations and distinct communities in which they serve.

Although IL Title V is able to administer the Block Grant and move forward with its action plans, it recognizes that its current staff are operating at their fullest capacity and there is a need to recruit additional talent to develop and implement new initiatives. Accordingly, IL Title V plans to fill vacant staff positions and create new positions in the near future. Currently, IL Title V leadership has completed interviews for a Maternal and Infant Health Coordinator; and plans to hire a new School Health Administrator before the end of the year. Additional positions planned for near future include two dedicated Title V epidemiologists, a Title V Grant Coordinator, and a school health manager/coordinator.

**UIC-DSCC**

UIC-DSCC is a statewide program serving CYSHCN through care coordination and other coordinated efforts to create improvements in the systems of care serving CYSHCN in Illinois. UIC-DSCC now has 365 staff working in 12 offices throughout the state. Although only a portion of funding for the DSCC programs comes from Title V, it is the collaboration of the statewide team along with the community-based relationships of the team members that enables UIC-DSCC to have greater awareness of the adequacy and effectiveness of systems of care serving CYSHCN in Illinois. UIC-DSCC has partnerships in place with many state, health related, and other service-based providers throughout the state. Examples include: IDPH, IDHFS, IL Department of Human Services (DHS, which includes Illinois’ Part C Early Intervention, home visiting and other early childhood programs, behavioral health, developmental disability, and rehabilitation services program), the Department of Child and Family Services, Illinois State Board of Education, local schools, children’s hospitals across the state and in bordering areas, pediatric primary and specialty care providers, licensed home nursing agencies, durable medical equipment vendors, and numerous public health, human service, and allied health care providers. Team members across the state participate in various community outreach events. Additionally, staff frequently attend clinic rounds. Attendance at these rounds provides opportunities for the UIC-DSCC team to share knowledge about resources that may help CYSHCN served by that program. UIC-DSCC uses a person-centered approach to care plan development and has incorporated person-centered methodologies into its policies and procedures.

The majority of the UIC-DSCC team is involved with care coordination. In recent years, UIC-DSCC has been working to promote a greater level of awareness amongst its staff of the role UIC-DSCC plays in Title V. This is intended to help develop greater understanding of staff across the state in identifying and reporting systematic issues impacting CYSHCN. Previously the care coordination teams, and dedicated Title V staff were in separate program units, but in the spring of 2020 these units have been combined under the same leadership. This will enable improved connection and awareness of the various
systematic projects in which UIC-DSCC is involved.

UIC-DSCC has a Family Advisory Council and a paid parent liaison that sits on the council. Currently, UIC-DSCC is revising the Family Advisory Council to update its purpose and effectiveness representing the broad needs of CYSHCN. Dedicated staff also work with families to help them better understand their insurance benefits and how to maximize available coverage. Financial assistance is available to eligible participants to cover expenses not covered by Medicaid or other insurance.

Thomas F. Jerkovitz, MPA, CPA is the Executive Director of UIC-DSCC. He has served in the Governor's Office as Senior Policy Advisor for Health and Human Services, as the Division Chief for the Medical, Child Welfare, and Health and Human Services in the Governor's Bureau of the Budget, as the Executive Director of the Illinois Comprehensive Health Insurance Plan (ICHIP), and as Director of Finance for Health Alliance Medical Plans, Inc.

III.C.2.b.ii.c. MCH Workforce Capacity

IDPH-MCH Title V Workforce
Title V has a total of 13 FTEs exclusively paid by IL Title V. An addition 5 IDPH OWHFS staff provide, in part, leadership, grant or fiscal support. Staff is located in Springfield, IL and Chicago, IL. The majority of the invited staff (n=16/18 or 88%) completed the Workforce Survey; the OWHFS Deputy Director, 11 MCH Title V-funded staff, including the Title V Director, 3 individuals self-identifying as general administration (e.g. fiscal manager), and 1 identifying as ‘other’. The IDPH-MCH Title V staff are relatively new; 10 respondents have only been with the IL Title V for four or fewer years. Unlike the rest of the nation (Maternal and Child Health Workforce Needs, AMCHP, 2017), in which the Title V workforce is aging, the IDPH-MCH workforce is young with 12/16 respondents reporting that they are 45 years or younger. However, similar to the rest of the nation, the IL IDPH-MCH Title V workforce is highly educated, with 15/16 respondents having at least a bachelor’s degree, 8 with a master’s (3 with an MPH), and 3 with a PhD (includes the CDC MCH EPI assignee).

The IDPH-MCH staff reported a number of training needs: using a systems approach to design and implement interventions (75%); translating and communicating data including data visualization (69%); using data for decision-making (56.3%); incorporating health equity principles into efforts (56.3%); communicating clearly with stakeholders and partners (56.3%); and, both basic and complex data analysis (56.3% for each of these). Several of these training needs were also identified in the Partner Survey, suggesting that going forward, an external party might be called on to provide joint training to MCH-IL Title V staff and their partners. IL Title V Leadership were asked about the main factors affecting training of their staff and agreed that registration cost, time commitment, availability of online training, and organization or supervisor support to attend the training are all important variables. With respect to the other respondents, there was not one major factor affecting their ability to participate in training, although the ability to receive continuing education credits is the least influential factor.

UIC-DSCC Title V Workforce
The majority of invited staff (n=184/226 or 81%) from the UIC-DSCC completed the Workforce Survey: the Division Executive Director, 175 DSSC staff, 2 staff members self-identifying as general administration (e.g., fiscal manager), and 6 identifying as ‘other’. About half the staff were new, having worked fewer than two years at DSSC (n=92, 50.3%); 35 respondents had worked for two to four years, 22 for five to nine years, and the remainder for 10 or more years. The majority of the DSSC workforce are 45 years old or younger (59.4%); thirty six percent are 46 to 64 years (36.3%). Similar to the IDPH-MCH Title V workforce, the DSSC workforce is highly educated, with 61 of 180 respondents having at least a bachelor’s degree, 105 with a master’s degree (2 with an MPH), and 2 with a doctoral degree. The DSSC respondents self-identified ethnicity as: non-Hispanic white (52.7%); non-Hispanic black (21.2%) and Hispanic (14.7%). Six respondents reported another non-Hispanic identity, and sixteen preferred not to
answer.

The UIC-DSCC staff reported a number of training needs including: understanding continuous quality improvement strategies (69.0%); incorporating health equity principles into efforts (65.2%); using a systems approach to design and implement interventions (62.5%); identifying evidence-based or evidence-informed practices (59.8%); incorporating life course principles into efforts (55.4%); and communicating clearly with stakeholders and partners (51.1%). In addition to these areas, leadership would like to provide additional staff training in the use of data for decision-making and program planning; basic data analysis-counts/frequencies, and simple graphs/charts; complex analysis-regression/GIS mapping; and literature reviews.

UIC-DSSC staff reported several factors influencing their ability to participate in professional development or continuing education (CE) opportunities. These factors included: availability of online training options; organization or supervisor support to attend training (47.8%); location and ability to receive continuing education units (46.7%); and registration cost and organization/program professional development requirements (44.6%). UIC-DSSC Leadership agreed that these factors and time constraints influenced staff training opportunities.

III.C.2.b.iii. IL Title V Partnerships, Collaboration and Coordination

As mentioned above in the Agency Capacity, Title V collaborates and partners with various stakeholders to expand the State’s capacity and reach in meeting the needs of the MCH population. For purposes of the needs assessment, the IL Title V convened an Expert Panel (EP); conducted partner assessment and collaborated with other MCHB investments.

**Expert Panel**

EP members were deliberately chosen for their MCH expertise related to the 2021-2025 Title V priorities, and their potential to identify strategies that would expand collaborative work and partnerships across the state, and further the development of a system of care for IL women, infants, children, and families. Their ideas for system development and enhancements are described previously in the *Systems* subsection of MCH Population Health Status. Visions for partnerships, alliances, and collaborative efforts generated by the EP discussions included: working within and across public and private sectors; thinking outside of the box in terms of who is/can be a partner; creating and supporting multidisciplinary partnerships across universities, community based health and social organizations, and the corporate world; applying a life course approach in collaborative relationships; creating a continuum for quality primary, secondary, and tertiary health care; integration of oral health and primary health care across the life course; and, leveraging interest and resources of national and state professional organizations to address MCH priorities in IL. The EP Webinar summaries contain a complete list of suggested collaborative opportunities (Appendix G).

**Partner Assessment**

Because the EP represented the State’s key internal and external stakeholders, they were also asked to participate in the Partner Survey. About half of the EP members (n=36/71) responded to the partner assessment: 32 who partner primarily with IDPH-MCH and 4 who partner primarily with UIC-DSCC. Overall, 31% of respondents were health care providers and 31% were from federal, other state or city public agencies. Most serve Title V populations: pregnant women (75%), infants (72%), adolescents (60%) and children (50%). One third of respondents stated they serve CYSHCN. The partners primarily interact with Title V by serving on task forces/committees, providing expert advice, and as funding recipients. Going forward, almost 100% of recipients expressed a desire to serve on task forces/committees, 85% would provide expert advice, and 75% were interested in receiving funding. Among those who interact with the CDC MCH Epidemiology Field Assignee, most receive data and technical assistance related to using data. Going forward, 85% desired to receive routine data, 88%
wanted to receive data as needed, and 78% wanted to receive technical assistance.

Partners were asked to reflect on program functioning and provided a very positive assessment of IL Title V’s leadership, partnership, and communication. Almost 70% of those reflecting on IDPH-MCH and 50% of those reflecting on IDPH-DSCC believed that the Title V staff always demonstrate clear and consistent purpose in their work. Almost 70% of those reflecting on IDPH-MCH indicated that Title V always demonstrate cooperative relationships with partners; for those reflecting on DSCC staff, 75% stated that DSCC always or usually demonstrate cooperative relationships with partners.

Regarding technical assistance, the greatest needs expressed by partners were: incorporating health equity principles into efforts (81%), translating and communicating data including data visualization (72%), using a systems approach (59%), and conducting complex data analysis (59%). The respondents reported that the most convenient modes for training are webinar (72%), online education course (64%), and peer to peer learning collaborative (58%). Most partners wanted information about Title V’s efforts through quarterly newsletters, annual reports, and periodic emails.

In open ended questions about partners’ vision of future IDPH-MCH activities, the most frequent comments referred to data sharing (including with consumers), data reporting, and data analysis. DSCC partners were more likely to discuss specific needs related to CYSHCN (e.g., care coordination).

**MIECHV Collaboration**

For the 2020 NA, collaboration and alignment between Title V and MIECHV was required by the HRSA’s Maternal and Child Health Bureau. In IL, this required concerted effort since the state’s MIECHV program sits in a separate state agency (the Governor’s Office of Early Childhood Development).

These parties worked together to support each other in several ways: (1) Title V providing data to MIECHV, (2) serving on each other’s NA advisory councils, (3) hosting joint coordination calls, and (4) including home visiting questions on the Title V NA public input survey.

**Other Partnerships (Internal and External)**

IDPH implements Illinois’ Title V through collaborations and partnership between IDPH, the Illinois Department of Human Services (DHS), Illinois Department of Healthcare and Family Services (HFS), and the University of Illinois at Chicago (UIC). IDPH maintains an intergovernmental agreement with the UIC Center of Excellence in MCH to obtain epidemiologic support and assistance.

Title V also collaborates with other internal IDPH program areas and external stakeholders. Internal partners include the Office of Minority Health, the Division of Vital Records, the Division of Patient Safety and Quality, the Division of Chronic Disease, birth defects program, and Pregnancy Risk Assessment Monitoring System (PRAMS). External partners include the Governor’s Office of Early Childhood Development, Illinois Early Learning Council, Illinois Home Visiting Task Force, Illinois Perinatal Quality Collaborative, and EverThrive Illinois, the organization that helps IDPH engage consumers to discuss barriers that families encounter in accessing health services and programs and provide recommendations for improvements to public health systems.

UIC-DSCC maintains close relationships with all major public and private agencies involved in services for CYSHCN, including the Illinois Chapter of the American Academy of Pediatrics (ICAAP) Committee on Children with Disabilities, the Arc of Illinois’ Family-to-Family Health Information Center (F2F), the Illinois LEND program, Illinois Interagency Council on Early Intervention, Coordinating Council on Transition, Illinois Universal Newborn Hearing Screening Advisory Committee, Illinois Genetics and Metabolic Diseases Advisory Committee, and IFLOSS (Coalition for Access to Dental Care). UIC-DSCC collaborates with the Sickle Cell Center at the University of Illinois Hospital and Health Sciences System (including the Sickle Cell Transition Adolescent-Adult Readiness [STAR] Clinic) to pilot a new model of care delivery for children and adolescents with Sickle Cell Disease. It also convenes a Medical Advisory
Board (MAB) that discusses how DSCC can enhance care coordination services for CSHCN.

III.C.2.c. Identifying Priority Needs and Linking to Performance Measures -

The Illinois Title V priorities were developed early in the Needs Assessment process through feedback with the Title V Advisory Council. As discussed in the Needs Assessment process section, the Advisory Council was a group of external professional stakeholders (n=12) with ties to the IL Title V or other MCH efforts in Illinois. It was first convened in early 2019 and charged with providing commentary on current MCH issues and advising on additional data needs or changes to the Needs Assessment process.

The first Advisory Council meeting was held in April 2019 and included a facilitated discussion about the MCH data sheets to identify areas of concern, gaps in measurement, and topics needing further attention from Title V. A second Advisory Council meeting in July included homework for members to further reflect on the data sheets and on the previous Title V priorities from 2016-2020. After the July 2019 meeting, Advisory Council members were asked to finalize their positions on keeping, revising or removing each of the 2016-2020 priorities.

Title V staff compiled the feedback from the Advisory Council members and synthesized comments about opportunities to refine existing priorities and to create new priorities. Advisory Council members gave feedback that framing the priorities in terms of systems and infrastructure issues would best align with the work of the IL Title V, rather than focusing on provision of specific services. Additionally, Advisory Council members highlighted several topics that were within the Title V scope that should be considered for inclusion as a priority, including: maternal health (more specifically than just reference to “birth outcomes”), child health beyond the early childhood years, and oral health.

Reflecting on the 2016-2020 priorities, the Advisory Council also recommended that IDPH conceptually change how it integrated health equity and consumer engagement in its priorities. During 2016-2020, there were two specific cross-cutting priorities on these topics. However, it was suggested that both health equity and consumer engagement should be pillar activities relevant to all future Title V efforts and initiatives, so they should be promoted to overarching principles for all priorities, rather than being individual priorities of their own. During the July AC meeting, this proposal was validated. The AC recommended adding a priority for maternal and postpartum health, broadening the child focused priority from 2016-2020, and including system-level language in the adolescent priority.

Similar to IDPH’s approach, UIC-DSCC reviewed its two priorities from 2016-2020 with its Medical Advisory Board to determine if they could be strengthened, to see if they aligned with the data from the Needs Assessment, and if they provided opportunity for UIC-DSCC to expand its future activities. UIC-DSCC determined that efforts to prepare CYSHCN for the transition to adulthood, a current priority, would be continued and there were additional opportunities for Title V to support training on transition in physician practices. UIC-DSCC developed a new priority to focus on convening and collaborating with community-based organizations to improve and expand services and supports for children with special health care needs. This priority will help UIC-DSCC move away from the direct service level of the pyramid and toward population-based and infrastructure-building services that will change the health care and support service landscape for CYSHCN in Illinois.

The proposed set of ten MCH priorities for 2021-2025 were sent to Advisory Council members for comments and approval in December 2019. Email communication with the Advisory Council generated overwhelmingly positive feedback on the proposed 2021-2025 priorities and resulted in only minor wording changes.

The Illinois Title V Priorities selected for FY 2021-2025 are shown in the table below, which summarizes whether they are continued or new priorities and the rationale for their inclusion:
<table>
<thead>
<tr>
<th>Domain</th>
<th>Priority</th>
<th>Type</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women’s/ Maternal</td>
<td>#1: Assure accessibility, availability and quality of preventive and primary care for all women, particularly for women of reproductive age</td>
<td>Continued</td>
<td>Advisory Council recommended continuing this priority to address overall health of all women of reproductive age.</td>
</tr>
<tr>
<td>Women’s/ Maternal</td>
<td>#2: Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum</td>
<td>New</td>
<td>Advisory Council recommended a priority to specifically address the health of women during pregnancy and the postpartum period to affirm the importance of these outcomes for the woman and not only focus on birth/infant outcomes.</td>
</tr>
<tr>
<td>Perinatal/ Infant</td>
<td>#3: Support healthy pregnancies to improve birth and infant outcomes</td>
<td>Continued</td>
<td>Advisory Council recommended continuing this priority.</td>
</tr>
<tr>
<td>Child</td>
<td>#4: Strengthen families and communities to assure safe and healthy environments for children of all ages and enhance their abilities to live, play, learn, and grow</td>
<td>New</td>
<td>Advisory Council recommended broadening the child health priority to go beyond just the early childhood period, but to be inclusive of children of all ages. A focus on assuring safe and healthy environments can encompass many diverse child health activities of Title V.</td>
</tr>
<tr>
<td>Adolescent</td>
<td>#5: Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors</td>
<td>Revised</td>
<td>Advisory Council recommended changing the framing of the old adolescent health priority to include system-level language, rather than focusing on individual behavior change.</td>
</tr>
<tr>
<td>CYSHCN</td>
<td>#6: Strengthen transition planning and services for children and youth with special health care needs</td>
<td>Continued</td>
<td>This priority was continued from the previous cycle and focuses on improving transition services for all adolescents, including youth with special health care needs.</td>
</tr>
<tr>
<td>CYSHCN</td>
<td>#7: Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs.</td>
<td>New</td>
<td>This priority will promote population-based and infrastructure-building services by the Illinois CSHCN program.</td>
</tr>
<tr>
<td>Cross-Cutting</td>
<td>#8: Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders.</td>
<td>Revised</td>
<td>Illinois had a previous priority on mental health and substance use services and systems, but this priority wording was revised to focus on workforce capacity and infrastructure – functions that Title V is more realistically able to address than service availability.</td>
</tr>
<tr>
<td>Cross-Cutting</td>
<td>#9: Support an intergenerational and life course approach to oral health promotion and prevention.</td>
<td>New</td>
<td>Advisory Council recommended adding a priority specific to oral health across the life course. Title V has supported oral health work in Illinois for many years, but it has not been a specific state priority in recent cycles.</td>
</tr>
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</table>
In addition to the ten priorities, Illinois Title V has set up four specific standards for each priority that will be addressed each year of the 2021-2015 cycle. These are additional expectations for the ways that Title V will address the priorities and carry out the state MCH action plan. The four standards that will be applied to each priority will include:

- Each priority will have at least one evidence-based program or strategy.
- Each priority will have one mechanism for routine feedback from consumers, families and communities to guide decision-making and program planning throughout the grant cycle.
- Each priority will have one communication product (e.g. infographic or report) annually highlighting an IL Title V or a relevant health outcome.
- Each priority will have at least one program or strategy that is applying a health equity framework.

RELATIONSHIP OF PRIORITIES TO NATIONAL AND STATE PERFORMANCE MEASURES

The fifteen available national performance measures (NPM) were considered in light of the selected state priorities and the proposed action plan for each priority. Illinois prioritized selection of measures that mapped well conceptually to the priority needs, but also has at least one related strategy in the state action plan. Given that many of the Title V priorities are infrastructure- and systems-focused, priority was also given to those NPM that focused on the health system or services (rather than specific health behaviors or outcomes). The Title V Director and MCH epidemiology team discussed the options and ultimately selected the following NPM:

**Women’s / Maternal Health:**

*NPM #1: Well-woman visits
NPM #2: Low-risk cesareans

**Perinatal / Infant Health:**

*NPM#3: Very Low Birth Weight Babies Born in Level III Hospitals
NPM #4: Breastfeeding

**Child Health:**

*NPM #6: Developmental screening for young children

**Adolescent Health:**

*NPM #10: Adolescent well visits

**Children with Special Health Care Needs:**

*NPM #12: Transition services for youth

**Cross-Cutting:**

*NPM #13-1: Preventative dental services for pregnant women
*NPM #13-2: Preventative dental services for children
The priority measures that were not selected included: #5 (safe sleep), #7 (injury), #8 (physical activity), #9 (bullying), #11 (medical home), #14 (smoking), and #15 (adequate insurance). For the most part, the rationale for not selecting these measures was that Illinois does not have any specific strategies in the action plan that would be expected to reasonably affect these measures on a statewide basis. That said, Illinois will consider whether any of these measures should be added in a future year as the state MCH action plan is revised and expanded. For example, the IL Title V has interest in doing more to affect physical activity and bullying in the future, but it is still exploring what avenues to use for that work.

After the eight national performance measures (NPMs) were selected for Illinois, the NPM were mapped to the priorities. This allowed for identification of priorities without a related NPM, and for identification of priorities where the associated NPM did not fully represent the Illinois MCH action plan. These gaps in measurement sparked discussion between the MCH epidemiology team, the Title V Director, and the DSCC team to brainstorm potential state performance measure topics, data sources, and indicators.

After NPM selection, there were three Illinois priorities without an associated NPM: #7 (CSHCN community systems building), #8 (mental health and substance use), and #10 (MCH epidemiology capacity and data systems). In addition, for priority #6 (safe and healthy environments for children) it was determined that the NPM on developmental screening alone did not represent the breadth of Illinois work on child health and that a SPM should be considered in addition to the NPM. After discussion between Title V leadership and the MCH epidemiology staff about available data sources and potential indicators, five SPM were developed to address topics of: difficulties with accessing needed care, family partnership in decision-making for care, difficulties obtaining mental health services, discussions of depression during pregnancy, and a composite score for data access, utilization, and reporting.

The table below gives the full NPM/SPM indicator names and their linkages with the Illinois Title V priorities for 2021-2025. More information about the specifications for the SPM is available in Form 10.

**Table: Linkage of Illinois Title V Priorities to National and State Performance Measures**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Priority</th>
<th>Performance Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women/Maternal</td>
<td>#1: Assure accessibility, availability and quality of preventive and primary care for all women, particularly for women of reproductive age</td>
<td>NPM 1: % women ages 15-44 with a preventative health visit in the last year</td>
</tr>
<tr>
<td>Women/Maternal</td>
<td>#2: Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum</td>
<td>NPM 2: % cesarean deliveries among low risk first births</td>
</tr>
<tr>
<td>Perinatal/Infant</td>
<td>#3: Support healthy pregnancies to improve birth and infant outcomes</td>
<td>NPM 3: % VLBW infants born in a hospital with a level III+ neonatal intensive care unit (NICU)</td>
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<td></td>
<td></td>
<td>NPM 4A: % infants ever breastfed</td>
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<tr>
<td></td>
<td></td>
<td>NPM 4B: % infants exclusively breastfed for at least 6 months</td>
</tr>
<tr>
<td>Domain</td>
<td>Priority</td>
<td>Performance Measures</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Child</td>
<td>#4: Strengthen families and communities to assure safe and healthy environments for children of all ages and enhance their abilities to live, play, learn, and grow</td>
<td>NPM 6: % of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year</td>
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<tr>
<td></td>
<td></td>
<td>SPM 3: % children (ages 3-17) who needed mental health services but had difficulties accessing them</td>
</tr>
<tr>
<td>Adolescent</td>
<td>#5: Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors</td>
<td>NPM 10: % adolescents (ages 10-17) who received a well visit in the last year</td>
</tr>
<tr>
<td>CSHCN</td>
<td>#6: Strengthen transition planning and services for children and youth with special health care needs</td>
<td>NPM 12: % adolescents, ages 12 through 17, with a preventive medical visit in the past year</td>
</tr>
<tr>
<td>CSHCN</td>
<td>#7: Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs.</td>
<td>SPM 1: % CSHCN whose parents reported unmet need for health services and frustration obtaining health care for their child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPM 2: % CSHCN whose parents reported feeling they were partners in decision-making for their child’s care</td>
</tr>
<tr>
<td>Cross-Cutting</td>
<td>#8: Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders.</td>
<td>SPM 3: % children (ages 3-17) who needed mental health services but had difficulties accessing them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPM 4: % women recently delivering a live birth who had a health care provider discuss depression with them during pregnancy</td>
</tr>
<tr>
<td>Cross-Cutting</td>
<td>#9: Support an intergenerational and life course approach to oral health promotion and prevention.</td>
<td>NPM 13.1: % women who had a preventive dental visit during pregnancy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NPM 13.2: % children, ages 1 through 17, who had a preventive dental visit in the past year</td>
</tr>
<tr>
<td>Cross-Cutting</td>
<td>#10: Strengthen the MCH epidemiology capacity and data systems</td>
<td>SPM 5: Score for access, utilization, and reporting of ten MCH data sources</td>
</tr>
</tbody>
</table>

National and state performance measures will be used to highlight the impact of Illinois Title V on MCH populations across the life course. Objectives for each NPM and SPM were developed based on an assessment of recent trends and a prediction of realistic progress that could be made in another 5 years.

III.D. Financial Narrative

III.D.1. Expenditures

**FY19 Report- Expenditures**

The Illinois Department of Public Health (IDPH) expended $18,917, 177.73 of its $21,103,272.00 allocation of Title V dollars in Grant Fiscal Year (G FY) 2019. This amount includes administrative costs. The remaining approximately $2.2 million will be spent before the end of the current award on September 30, 2020. There are multiple reasons for this unspent balance, including an unexpected
pandemic (COVID-19), reduction in workforce (staff turnover leading to reduction in payroll costs as well as ability to implement grant projects) and a temporary lack of legislatively grant spending authority.

At the beginning of State Fiscal Year (SFY) 2019, IDPH had $20,750,000 in MCH Block Grant spending authority as follows:

- 5.0 million for an MCH grant to the Chicago Department of Public Health (CDPH)
- $7.0 million to the University of Illinois’ Division of Specialized Care for Children (UIC-DSCC) for CYSHCN programs
- $2.5 million for grants related to perinatal services for premature and high-risk infants and their mothers (the regionalized perinatal health care program)
- $6.25 million for all other expenses associated with maternal and child health programs

In late SFY 2019, the legislature granted IDPH an additional $1.5 million in spending authority on the budget line for all other expenses associated with maternal and child health programs, bringing IDPH’s total spending authority to $22,250,000.

For State Fiscal Year 2021, the MCH Block Grant spending authority was again increased, giving IDPH a $27,750,000 spending authority as follows:

- $6 million for an MCH grant to the CDPH
- $9 million UIC-DSCC
- $3 million for grants for the regionalized perinatal health care program
- $9.75 million for all other expenses associated with maternal and child health programs

This increase will allow IDPH to fully expend the federal Title V funds it receives each year. During GFY19, Illinois had the following breakdown of Title V spending/expenditures: 9% for Administrative Costs, 42% for Primary and Preventive Care for Children, 33% for Children and Youth with Special Health Care Needs (>30% of received allocation), and 16% for all other populations.

State MCH Programming (Match/Maintenance of Effort [MOE])

The MCH Block Grant funds complement the State’s total MCH investment. For GFY19, the state-funded expenditures (Match/MOE) was $27,756,991.62. This consisted of $25,590,116.00 in State funds and $2,166,875.62 in Local/Other funds. The bulk of the Match/MOE comes from DHS, where the IL Title V was originally housed. However, when Title V transferred to IDPH in 2014, IDPH received the federal allocation, but not the headcount/staff required to manage the moved programs nor the corresponding general revenue to support the programs. Consequently, many of the programs that fell under Title V remained at DHS along with almost 50% of the state-funded expenditures (Match/MOE).

The DHS state-funded programs included in the Title V Match/MOE are Parents too Soon, Birth to Three Institute, Family Case Management, Better Birth Outcomes, the All Our Kids Network (AOK), and Youth Services Support (career, training, and employment guides). This match is formalized through an annual interagency agreement (IGA) between DHS and IDPH which outlines data sharing, aligning of program outcomes, participation of DHS in the Title V needs assessment process, and routine meetings between MCH program leads at each agency. It also ensures proper documentation of state general revenue funds being used as federal match.

In addition to the DHS programs, another source of Match/MOE funding is provided by state general revenue and special funding (including tobacco settlement dollars) administered by IDPH. These funds support the school-based health centers, the regionalized perinatal health care program, EverThrive Illinois partnership, Illinois Breast and Cervical Cancer Program, and the state’s Newborn Screening
Program. State general revenue also covers the salaries of the OWHFS Deputy Director, Assistant Deputy Director, and fiscal staff of which approximately 65% of the salaries contribute toward Match/MOE. It is noted that these positions are included because they support the administration of the Division of Maternal, Child, and Family Health Services where the IL Title V resides. UIC-DSCC provides another notable source of Match/MOE. Specifically, UIC-DSCC provides $4.75 million in state and local general revenue funds to provide services to children and youth with special health care needs.

In an effort to monitor its funds and best leverage them for improving the health of women, children and families across Illinois, the IL Title V holds monthly meetings with OWHFS’ Fiscal Manager and quarterly meetings with its grantees. In addition, IDPH requires its grantees to provide monthly budget reports and quarterly progress reports.

Workforce Reduction

The IL Title V has a small workforce of approximately 18 individuals with 13 members exclusively paid by Title V. During the GFY19, IDPH has experiences workforce challenges that include several vacant key positions. At various times during the grant period, vacant positions included the Child and Adolescent Health Coordinator (filled), a dedicated Maternal and Infant Health position, Title V epidemiologist, dedicated school health data manager (filled), and official Title V Director (filled). Recently, IDPH hired a Maternal and Infant Health Coordinator; however, the epidemiology position has yet to be filled and a recent staff retirement has left the School Health Center Administrator program vacant. IDPH is working diligently to fill these positions as well as add additional key positions (e.g., a second epidemiologist, Title V Grant Coordinators) to increase the capacity of Title V to meet its charge of improving the health of women, children and families across Illinois. Despite these staff challenges, DPH-MCH IL Title V has continued to provide programs and services through the efforts of its staff as well as the establishment of collaborations and partnerships.

IL Title Vs

The following maternal and child health programs were supported with the IDPH portion of the State’s Maternal and Child Health funding during FY19:

Illinois Department of Human Services (DHS)
The Title V Block Grant funds various IL Title Vs being administered by DHS. Specifically, a portion of the Better Birth Outcomes Program that promotes home visiting and case management organizations providing screening, assessment, treatment, and psychiatric care for women who suffer from perinatal depression. Additionally, funding was provided to support the Fetal Infant Mortality Review (FIMR) and Perinatal Depression Hotline programs. FIMR and the Perinatal Depression Hotline Program will be transferred to IDPH for FY20 implementation.

MCH Mini-Grant

The Chicago Department of Public Health (CDPH) has been charged with implementing a localized version of the Title V Block Grant within the city of Chicago. Ongoing implementation of the grant has been challenging, due to the state’s shift away from a targeted direct-service approach to maternal and child health and towards population-based services which improve the health and well-being of all mothers, infants, and children within city limits. Additional highlights of CDPH’s programs are included in the domain narratives.

Regionalized Perinatal Health Care Program

The Regionalized Perinatal Health Care Program provides the infrastructure and support for Illinois’ birthing and non-birthng hospitals. The system consists of several health centers charged with engaging and supporting a network of hospitals, each with a perinatal level of care designation
based on resources and ability to care for neonates. These health centers are called Administrative Perinatal Centers (APCs). To meet their charge, they serve as a referral facility intended to care for the high-risk patient before, during, or after labor and delivery and are responsible for providing education, training, consultation, and transportation coordination for mothers and infants requiring complex healthcare services, to its network of birthing hospitals.

**School-Based Health Centers**
The School Health Center (SHC) Program monitors 66 certified school health centers operating in Illinois. These centers seek to improve the overall physical and emotional health of school age children and youth by promoting healthy lifestyles and by providing accessible preventive health care. Through early detection and treatment of chronic and acute health problems, identification of risk-taking behaviors and appropriate anticipatory guidance, treatment and referral, school health centers assure students are healthy and ready to learn. The Title V School Health Center (SHC) Program funds almost 60% of the certified school health centers in Illinois.

**Illinois Maternal and Child Health Coalition (EverThrive Illinois)**
This program is a collaboration with EverThrive Illinois that focuses on the maintenance and growth of the MCH Family Councils which serve as the primary community/consumer voice for the IL Title V. The program also supports the facilitation of statewide workgroups including one on Pre and Inter-Conception.

**Illinois Perinatal Quality Collaborative**
The Illinois Perinatal Quality Collaborative (ILPQC) has been funded for several years by the IL Title V. During FY19, the primary quality improvement initiatives included finishing and sustaining (i) the Severe Maternal Hypertension Initiative; and (ii) the Mothers and Newborns affected by Opioids Initiative. The ILPQC also plans and hosts an annual statewide in-person collaborative meeting for clinicians and public health practitioners and maintains a web-based data portal for data submission and visualization for hospital and partner use.

**Partnerships with IDPH Division of Oral Health**
The partnership with the Division of Oral Health (DOH) includes several programs that emphasize the importance of oral health for women during pregnancy, early childhood and for youth, in general. The Partnerships for Integrating Oral Health Care into Primary Care Program focuses on integration the interprofessional oral health core clinical competencies into primary care practice. Another key program of the partnership was the provision of dental sealant to children on Medicaid or without dental insurance.

**Data Collection, Analysis and Support**
The IL Title V has intergovernmental agreements with: (i) the University of Illinois at Chicago School of Public Health to provide epidemiological guidance and analytical support to Illinois’ IL Title V; and (ii) the University of Illinois at Chicago, Center for Research on Women and Gender to provide analytical support related to improving outcomes for women suffering from severe maternal morbidity.

Illinois Title V has contractual relationships with JEMM Technologies and Illinois PRAMS. JEMM Technologies provides a management information system (ePeriNet) that not only collects data, but also, generates reports for the Illinois’ perinatal system. The Illinois PRAMS project is also supported by Title V and uses funds for respondent incentives.

**Other Uses of Funding**
Title V funds help to supports other activities such as hosting the annual Illinois Women and Families’ Health Conference, and travel expenses for the Division of Maternal, Child, and Family Health Services for staff to conduct hospital site visits for the regionalized perinatal program, oversee site visits required for the
certification of school health centers, and attend professional development programs (e.g., AMCHP conference, CityMatch annual conference, American Public Health Association [APHA] annual conference).

**Children and Youth with Special Health Care Needs**

Thirty percent (30%) of Title V funding was passed through to UIC-DSCC to implement the state’s program for CYSHCN. UIC-DSCC uses its federal MCH Block Grant funds and matching University (state and local) funds to operate its Core Program. This includes expenditures for gap-filling direct services, care coordination (enabling services), population-based services, and supportive administrative systems. The Core Program provides care coordination, supports transition, and promotes family partnerships. Its activities are described in the State Action Plan.

UIC-DSCC expended $10.21 million from all federal, local, and state sources in FY19. This includes $5.43 million in federal Title V Block Grant Funds, $3.47 million in state general funds, and $1.28 million in local funds. The funds were distributed by type of services as follows: 50% for direct services ($2.17 million), 22% for enabling services ($1.19 million), and 28% for public health services and systems ($1.52 million). A closer examination of direct service expenditures revealed that UIC-DSCC spent $1.56 million (approximately 58%) on durable medical equipment and supplies to support CYSHCN. Non-federal expenditures for CSHCN totaled approximately $4.75 million in FY19 and was distributed at the same rate for type of services as the federal funding. Similar to federal spending, a little over half of the non-federal direct services funds were used to secure durable medical equipment and supplies. The amount of non-federal dollars expended for enabling services was $522,306 and for public health systems and services was $664,753.

**III.D.2. Budget**

**FY21 Application—Budget**

Illinois’ proposed budget for FY21 is based upon level Title V Block Grant funding in the amount of $21,129,026.00. For State Fiscal Year 2021, IDPH has $27,750.00 in MCH Block Grant spending authority as follows:

- $6 million for an MCH grant to the CDPH
- $9 million UIC-DSCC
- $3 million for grants for the regionalized perinatal health care program
- $9.75 million for all other expenses associated with maternal and child health programs

To better align funding with the MCH Priorities and Performance Measure outlined in the Title V Action Plan, Illinois proposes the following breakdown of Title V spending, which would be approximately 46 percent for preventive and primary care for children, 30% for children and youth with special health care needs, approximately 16% for all other populations, and an estimated 7% for administrative costs. Funds are projected to be spent according to the following rates:

<table>
<thead>
<tr>
<th>Types of Individuals Served</th>
<th>Types of Services Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant</td>
<td>Direct Services</td>
</tr>
<tr>
<td>Infant</td>
<td>15%</td>
</tr>
<tr>
<td>Children and Adolescent</td>
<td>21%</td>
</tr>
<tr>
<td>CYSHCN</td>
<td>30%</td>
</tr>
<tr>
<td>Other</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Direct Services</td>
</tr>
<tr>
<td></td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>Enabling Services</td>
</tr>
<tr>
<td></td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Public Health Services</td>
</tr>
<tr>
<td></td>
<td>and Systems</td>
</tr>
<tr>
<td></td>
<td>52%</td>
</tr>
</tbody>
</table>
State MCH Programming (Match/Maintenance of Effort (MOE))

DHS will continue to provide a large portion of the state-funded expenditures (Match/MOE) for maternal and child health including Family Case Management, All Our Kids Network (AOK), and Youth Services Support (career, training, and employment guides). This Match is formalized through an annual interagency agreement between DHS and IDPH which also outlines data sharing, aligning of program outcomes, participation of DHS in the Title V needs assessment process, and routine meetings between MCH program leads at each agency. It also ensures proper documentation of state general revenue funds being used as federal match.

Another major source of Match/MOE for the IL Title V is provided by state general revenue funding (including tobacco settlement dollars) administered by IDPH. These funds support a variety of state initiatives including the school-based health centers, regionalized perinatal health care program, EverThrive Illinois partnership, Illinois Breast and Cervical Cancer Program, and the state’s Newborn Screening Program. Salaries for the Deputy Director, Assistant Deputy Director and fiscal staff of the Office of Women’s Health and Family Services are funded by state general revenue and approximately 65% of their time is considered as Match/MOE for Title V due to their support and administration of the Division of Maternal, Child, and Family Health Services. As evidence of Illinois’ continued commitment to improving the health of MCH populations, Illinois increased general revenue funding for Title V in the beginning of FY21. Notably, half of the increase funding was directed towards the school-based health center program.

The University of Illinois Division of Specialized Care for Children also supports the Match/MOE with state and local general revenue funds used to serve children with special health care needs. There are no anticipated changes for FY21. Planned expenditures of non-federal funds include 50% for direct services, 22% for enabling services, and 28% towards public health services and systems.

Workforce

During FY21, it is anticipated that the following Title V staff positions will remain the same and are part of the administrative costs assessed to the MCH Block Grant:

- Registered Nurse/Perinatal Nursing Consultant #1
- Registered Nurse/Perinatal Nursing Consultant #2
- Registered Nurse/School Health Consultant #1
- Registered Nurse/School Health Consultant #2
- Registered Nurse/School Health Consultant #3
- School Health Program Administrative Support
- School Health Program Data Grant Manager
- Title V Director
- Adolescent and Child Health Coordinator
- Maternal Morbidity and Mortality Analyst (CDC-funded)

The Title V staff’s efforts will be assisted by the continued services of the CDC MCH Epidemiology Assignee who will continue to support two graduate student interns. In addition, IL Title V has secured two temporary positions that will contribute to its epidemiology capacity. A CDC COVID-19 Epidemiologist joined IDPH in July 2020 and will remain through June 2021. This position will implement CDC’s COVID-19 pregnancy module; support sentinel surveillance of COVID-19 among women presenting for labor and delivery; and measure the indirect effect of COVID-19 on maternal and child health. A CDC/CSTE Applied Epidemiology Fellow will join IDPH in August 2020 and will remain through August 2022. This fellow will focus on various epidemiology projects, including reviewing and analyzing data on fetal deaths, maternal morbidity, and opioid use and neonatal
abstinence syndrome.

While the IL Title V has been able to retain the majority of its staff and therein provide continuity of services as well as preserve institution knowledge, it is important to highlight the staff turnover experienced in FY20. These turnovers include the School Health Program Administrator retiring, the Data Manager/Epidemiologist leaving, and the Title V Administrative Assistant being promoted to another position. IDPH is seeking to fill these positions as quickly as possible. The Data Manager/Epidemiologist position will be split into two positions with each focusing on two specific population domains (see the domain designation stated below). The job description for the former Infant Mortality Reduction Coordinator was revised to the Maternal and Infant Health Coordinator who will oversee activities related to perinatal health in the state. Currently, this position is in the process of being filled.

In addition to filling the vacancies, IDPH is in the process of creating/refining three positions to be hired as soon as possible (this list includes the two Title V epidemiologist mentioned above):

1. Title V Block Grant Manager to help with annual report and streamlining existing grant programs
2. Maternal Mortality Review Operations Manager to support the activities of the Illinois Maternal Mortality Review Committee (MMRC) and Illinois Maternal Mortality Review Committee for Violent Deaths (MMRC-V) including assistance with data collection and data entry for performance reporting and grant evaluation.
3. Title V Epidemiologist (Maternal/Infant Health) to perform highly complex data management functions and assignments pertaining to surveillance, needs assessment, quality improvement and program planning activities related to maternal and infant health.
4. Title V Epidemiologist (Child/Adolescent Health) to perform highly complex data management functions and assignments pertaining to surveillance, needs assessment, quality improvement and program planning activities related to maternal and infant health.

IL Title V

Illinois proposes the following population-level programming for FY21, which aligns with the state’s identified MCH Priorities and Performance Measures:

**Illinois Department of Human Services (DHS)**

Title V funding for the Better Birth Outcomes program ended in FY19 and thus will not be included in the budget proposal for FY21. In addition, the Fetal Infant Mortality Review (FIMR) and the Perinatal Depression Hotline were transferred to IDPH and administered as a part of its Title V portfolio of programs. DHS will continue to administer its other Title V related programs which include the Parents Too Soon, Birth to Three Institute, Family Case Management, the All Our Kids Network (AOK), and Youth Services Support program.

**Fetal Infant Mortality Review (FIMR) and Perinatal Depression Hotline**

FIMR is a national model for reviewing the circumstances surrounding the stillbirth or death of an infant. The goal of the program is to develop community-level strategies which may improve birth outcomes for children. The current FIMR focuses on the Chicago area, but IL Title V is exploring the creation of a second FIMR in the State. The Perinatal Depression Hotline provides around-the-clock access to mental health professionals through a toll-free number.
**MCH Mini-Grant**
The Chicago Department of Public Health (CDPH) will be charged with implementing a localized version of the Title V Block Grant in Chicago. The grantee will be responsible for population-based services which improve the health and well-being of all mothers, infants, and children within city limits. CDPH will continue its activities in addressing several of the identified Title V priorities.

**Mental Health Consultation**
The Illinois Children’s Mental Health Partnership has been charged with developing a variation of the Infant Mental Health Consultation program—currently implemented in home visitation and early childhood settings—for the health care setting, including local health departments. This grant started in FY19 and continues through FY21.

**Regionalized Perinatal Health Care Program**
The Regionalized Perinatal Health Care Program provides the infrastructure and support for Illinois’ birthing and non-birthing hospitals. The system consists of several health centers charged with engaging and supporting a network of hospitals, each with a perinatal level of care designation based on resources and ability to care for neonates. These health centers are called Administrative Perinatal Centers (APCs). To meet their charge, they serve as a referral facility intended to care for the high-risk patient before, during, or after labor and delivery and are responsible for providing education, training, consultation, and transportation coordination for mothers and infants requiring complex healthcare services, to its network of birthing hospitals.

**School-Based Health Centers**
The School Health Program monitors 66 certified school health centers operating in Illinois. These centers seek to improve the overall physical and emotional health of school age children and youth by promoting healthy lifestyles and by providing accessible preventive health care. Through early detection and treatment of chronic and acute health problems, identification of risk-taking behaviors and appropriate anticipatory guidance, treatment and referral, school health centers assure students are healthy and ready to learn. The Title V School Health Center (SHC) Program funds almost 60% of the certified school health centers in Illinois.

**Adolescent Health Initiative**
During FY21, the Adolescent Health Initiative will build on the progress demonstrated by its 11 grantees in FY20. The grantees consist of ten local organizations that are supporting the local implementation of strategies and support to increase the percentage of adolescents who received preventive and primary health care, and the Illinois Chapter of the American Academy of Pediatrics, which continued to develop and provide training and support for health care providers to expand adolescent-friendly health care services including access to mental health services and programs.

**Well-Woman Care Mini-Grants**
During FY20, IL Title V supported approximately 14 entities as they developed and began to implement a plan to positively impact the number of women seeking well-woman care within their communities. In FY21, grantees will be expected to fully implement their plan and begin process evaluation.

**Illinois Maternal and Child Health Coalition (EverThrive Illinois)**
This program is a collaboration with EverThrive Illinois that focuses on the maintenance and growth of the MCH Family Councils which serve as the primary community/consumer voice for the IL Title V. The program also supports the facilitation of statewide workgroups including one on Pre and Inter-Conception. In FY21, this collaboration will expand the role of the Family Councils and well as leverage EverThrive’s ability to engage consumers and provide education.
Illinois Perinatal Quality Collaborative (ILPQC)
The Illinois Perinatal Quality Collaborative (ILPQC) has been funded by the IL Title V for several years. During FY21, the main quality improvement initiatives will be related to Mothers and Newborns affected by Opioids. The ILPQC also plans and hosts a statewide annual in-person collaborative meeting for clinicians and public health practitioners and maintains a web-based data portal for data submission and visualization for hospital and partner use.

The University of Illinois at Chicago, Center for Research on Women and Gender - Maternal Depression
This partnership focuses on the implementation of a pilot program at two clinic sites. The goal of the program is to pilot a combination of strategies to increase the capacity of perinatal providers to screen, assess, refer, and treat behavioral health disorders, and to increase awareness of and access to affordable and culturally-appropriate services to improve the mental health and well-being of pregnant and postpartum women and their infants in the State of Illinois.

Maternal Mortality Review Committee (MMRC) Support
The Title V Block Grant will continue to support the ongoing implementation of the State’s Maternal Mortality Review Committee and the Maternal Mortality Review Committee of Violent Deaths. These population-level reviews will identify recommendations for strategies and services to be implemented at the system, community, local, and patient levels to improve outcomes for mothers and children. Title V funding is used to (i) host the data collection site MMRIA (designed by the CDC); (ii) support the salaries of IDPH staff who are responsible for coordinating committee meetings and supporting the case identification and analysis process; and (iii) reimburse committee members, all of whom volunteer their time, for their travel to meetings.

Data Collection, Analysis and Support
Illinois will continue two intergovernmental agreements with the University of Illinois at Chicago. The first is with the School of Public Health to provide epidemiological guidance and analytical support to Illinois’ IL Title V. The second is with the Center for Research on Women and Gender to provide analytical support around improving outcomes for women suffering from severe maternal morbidity.
Illinois has entered into a contractual relationship for State Fiscal Year 21 with JEMM Technologies to maintain the existing data collection and reporting system for Illinois’ perinatal system, ePeriNet. The IL Title V will continue to provide funding to the Illinois PRAMS project for respondent incentives to improve survey response rate; this allocation will increase in FY21 to reflect an increase the cost of adding a COVID-19 supplement to the IL PRAMS survey.

Other Uses of Funding
Illinois’ IL Title V will continue to support activities such as hosting the annual Illinois Women and Families’ Health Conference, and travel expenses for the Division of Maternal, Child, and Family Health Services for staff to conduct hospital site visits for the regionalized perinatal program, oversee site visits required for the certification of school health centers, and attend professional development programs (e.g., AMCHP conference, CityMatch annual conference, American Public Health Association [APHA] annual conference).

In addition, the IL Title V will continue other initiatives at IDPH including an allocation to the Office of Oral Health, increased funding for the annual Illinois Women and Families’ Health Conference, and graduate student internships for injury/suicide prevention and the school-based health center program.

Children and Youth with Special Health Care Needs
The amount of federal Title V Block Grant funds budgeted for CYSHCN in FY21 is $6,338,708. The amount of general state funds that the UIC-DSCC expects to receive to serve CYSHCN is approximate $3.5 million and another $1.3 million in local funds.
UIC-DSCC expects the FY21 MCH Block Grant allocation of $6.34 million to be expended by type of service in amounts similar to FY20. Direct services spending at 50%, enabling services at 22%, and public health services and systems accounting for 28% of CYSHCN funds.
III.E. Five-Year State Action Plan

III.E.1. Five-Year State Action Plan Table State: Illinois

Please see separate Action Plan link provided on the IDPH webpage.

III.E.2. State Action Plan Narrative Overview

III.E.2.a. State Title V Program Purpose and Design

Illinois’ Title V Maternal and Child Health (MCH) Services Block Grant is implemented through a collaborative relationship between the Illinois Department of Public Health (IDPH), which administers the program and provides the infrastructure for the state’s maternal and child health programming, the Illinois Department of Human Services (DHS), which provides targeted interventions to improve the outcomes and life trajectory of the state’s most vulnerable families, and the Illinois Department of Healthcare and Family Services (HFS), the state’s Medicaid agency, responsible for providing health care coverage to low-income families in the state. In addition to the collaborative relationship between the three state agencies, Illinois’ services for families with children with special health care needs are provided by the University of Illinois at Chicago’s Division of Specialized Care for Children (UIC-DSCC) through an intergovernmental Agreement.

As the primary administrator of the State’s Title V Program, IDPH provides the infrastructure, or framework, for the state’s maternal and child health programming by promoting the findings from the MCH needs assessment, establishing a shared vision around the MCH priorities (which are collaboratively established as a result of the needs assessment), and by working to assure that national and state performance measures are widely known and accepted as performance indicators for all maternal and child programming within the state, regardless of the source of funding.

To achieve the Title V over-arching goal of improving the health and well-being of all Illinois mothers and children, there must be coordination and alignment in the contributions of all child/family-serving programs and systems.

Title V acts as the “convener,” bringing together key stakeholders to create a shared vision, or understanding, of the goals for Illinois’ mothers and children and to provide a framework through which we can align work and create synergy. Examples of these efforts include the development of Illinois’ State Health Improvement Plan, Healthy People 2021, which contains goals and strategies for MCH that align with the Title V priorities, the convening of cross-disciplinary stakeholders to create a shared vision for assuring that women receive preventive oral health care during pregnancy, and specifically connecting the I PROMOTE-IL Maternal Health Taskforce and Illinois’ legislatively mandated Task Force for Infant and Maternal Mortality Among African Americans to collaborate on addressing maternal mortality in Illinois with a social determinants of health and health equity lens.

UIC-DSCC assists children and youth with chronic health conditions that require specialized medical care. Children are referred to UIC-DSCC by many other agencies. IDPH screening programs for metabolic diseases and hearing loss and the Adverse Pregnancy Outcomes Reporting System (APORS) are important referral sources, as are the DHS’ Part C and Supplemental Security Income (SSI) programs. Many of UIC-DSCC’s regional staff routinely participate in rounds held by the specialty services in Illinois’ children’s hospitals and clinics. This is an important referral source and provides a regular opportunity for UIC-DSCC staff to interact with families of CYSHCN and with pediatric care providers as well as to inform them of community resources that may be able to assist families, regardless of their participation in UIC-DSCC care coordination. Statewide, UIC-DSCC participates in over 60 different rounds or clinics each month.
UIC-DSCC also participates in many community outreach events and professional conferences to make the public and service providers aware of its services. An active presence on social media is also maintained to distribute information of interest to all CYSHCN and their families, not just those who participate in UIC-DSCC care coordination.

The Core Program coordinates care for CYSHCN who have a condition that falls into any one of 11 system-based categories of medical conditions, which include cardiovascular, eye, gastrointestinal, hearing, nervous system, orthopedic, pulmonary, and urogenital impairments; craniofacial and external body impairments; blood disorders; and inborn errors of metabolism. UIC-DSCC also performs a financial gap-filling role for lower-income families in the Core Program.

The Home Care Program operates one of Illinois’ Home and Community Based Services Waivers by coordinating care for children, youth, and, in certain circumstances, adults who are medically fragile and often technology dependent. The program is also the state’s single point of entry for children receiving in-home shift nursing services as a part of the Medicaid program. Children must be under 21 years of age at the time of enrollment and have a health condition that requires nursing care to avoid hospital admission or placement in a long-term care facility. Family income is not considered in the determination of eligibility. The Home Care Program also provides in-home nursing and care coordination services to children and youth with less complex needs. These families must be financially eligible for Medicaid to qualify for these services.

UIC-DSCC defines care coordination as a person- and family-centered, strength-based, assessment-driven approach to empowering families to achieve their goals, ultimately leading to positive health outcomes, improved quality of life, and overall family satisfaction. DSCC’s care coordination efforts focus on partnering with families and communities to help CYSHCN connect to the services and resources they need to reach their full potential. Regional care coordination teams use a comprehensive and holistic assessment and work with the family to develop a person-centered plan.

This plan also supports each family’s partnership with its medical home as well as helps families understand and follow their providers’ treatment plans and communicate more effectively with everyone involved in the child’s care. This is consistent with UIC-DSCC’s vision for placing CYSHCN and their families at the center of a seamless support system that improves the quality of their lives.

The comprehensive assessment focuses on five domains: medical, social/emotional, education, financial, and transition. The assessment identifies health risks, social risks, and the family’s ability to participate in their child’s care. It informs staff of where our participants live, learn, work, and play so that they understand how the family’s physical and social environment affects their health and their ability to follow their medical home’s treatment plans. Assessment is an ongoing learning process for staff and families and not a single event or annual meeting. It is an information-gathering process that captures what the participant and their family want in their life, the supports needed, and their perspective on how they want to live. It also draws on information from providers and a review of medical and other documentation.

Care coordinators and families develop a person-centered plan based on the comprehensive assessment. The plan is shared with the family’s medical home, so the home is aware of and understands the barriers and resources the family needs to support continued health and success. This information is used to educate both the family and the provider about community resources and supports.

Care coordinators come from a variety of professional backgrounds including nursing, social work, audiology, and speech pathology. Staffs collaborate to bring a multidisciplinary approach to
assessment, care planning, and service delivery.

Contact with families occurs through home visits, meeting attendance (e.g., meetings to develop early intervention or special education service plans), phone calls, mail, or email.

UIC-DSCC works with many government agencies and service providers to better organize and strengthen the system of care for CYSHCN and their families through collaborations with the state’s children’s hospitals, and the state’s Title XIX and Title XXI programs. UIC-DSCC staff also participates in meetings of the Child Care Advisory Committee, the Home Visiting Task Force, the Illinois Children’s Justice Task Force, the National Advisory Panel on Access and Quality of Home Health Care for Children, and other state-level advisory groups.

**Supporting Systems**

*IL Title V*

A main supportive administrative system is the Perinatal Advisory Committee (PAC), which is an advisory body to IDPH. The purpose of PAC is to advise IDPH on the establishment and implementation of policy related to perinatal and maternal care. Its duties and responsibilities are set forth by the Developmental Disability Prevention Act (410 ILCS 250) and the Regionalized Perinatal Health Care Code (77 Ill. Admin. Code 640). The committee is required to meet at least four times in a calendar year and these meetings are open to the public for attendance and comment. PAC advises IDPH on a multitude of issues and gives IDPH technical insight from the hospital, provider, and community perspectives.

PAC also oversees several sub-committees which consist of: (1) the Statewide Quality Council (SQC); (2) Hospital Facilities Designation Committee (HFDSC); (3) Maternal Mortality Review Committee (MMRC); (4) Maternal Mortality Review Committee on Violent Deaths (MMRC-V); and (5) the Severe Maternal Morbidity (SMM) Review Committee. The SQC works closely with Illinois’ Regional Perinatal Network Administrators on different statewide initiatives and projects. The HFDSC looks at Illinois’ hospital level of care designations and helps IDPH make formal decisions when a hospital intends to increase or decrease their level of care and assures compliance with the Regionalized Perinatal Health Care Code. The MMRC reviews Illinois’ clinical maternal deaths and recommends actions that could have helped prevent the death. The MMRC-V functions the same as the MMRC, but reviews deaths resulting from drug overdose, homicide, or suicide. The MMRC and MMRC-V consider not only what the hospital and provider could have done differently, but also target patient education, socioeconomic, community, and health care systems factors. The purpose of the SMM Review Committee is help standardize maternal morbidity reviews performed at the APC and hospital levels.

The IL Title V administrative assistant supports all functions of these committee meetings including, but not limited to, compliance with the Open Meetings Act and State Officials and Employees Ethics Act, membership coordination, logistics coordination, minute-taking, technical assistance, and serving as an IDPH liaison. A representative from the PAC must also attend every hospital re-designation site visit in alignment with the Regional Perinatal Health Care Code. The administrative assistant also coordinates with the PAC to ensure that one of their members attends each of these visits.

*CYSHCN*

UIC-DSCC’s Care Coordination unit oversees all the regional staff in both the Core and Home Care Programs. UIC-DSCC operates 11 regional offices across the state to facilitate family access and to support the development of community-based service delivery. The Core and Home Care Programs
each have a Quality Improvement Team (QIT); refer to the “Needs Assessment Update” section for more information.

III.E.2.b. Supportive Administrative Systems and Processes

III.E.2.b.i. MCH Workforce Development

IL Title V

Organizationally, the Illinois Title V Director leads the Division of the Maternal, Child, and Family Health Services, and reports to the OWHFS Deputy Director, Shannon Lightner, MPA, MSW. The current Title V Director is Kenya D. McRae, JD, PhD, MPH, MBA who joined OWHFS in October 2019. Dr. McRae has an MPH in Epidemiology from George Washington University and a PhD in Public Health, Community Health Sciences, Behavior Health and Health Education from the University of Illinois at Chicago. She has over 15 years of experience in public health and research.

The IL Title V is supported by several key personnel. Trishna Harris, DNP, APN, WHNP- BC, CNM, and Miranda Scott, MBA, MALs, BSN, RN, LNC. Ms. Harris and Ms. Scott, serve as perinatal health nurses responsible for working directly with Illinois Regional Perinatal Networks and birthing hospitals to assure that health care services meet the standards of care identified in the state’s administrative code. Kelly Vrablic, MS, MPH, is the Adolescent and Child Health Coordinator, responsible for the Adolescent Health Initiative and increasing adolescent well-visits as well other programs to improve the health of Illinois’ children and adolescents. Alexander Smith, BA, provides administrative support to the Division of Maternal, Child, and Family Health Services, including scheduling, computer issues, and maintenance of advisory groups such as the Perinatal Advisory Council. The School Health Program includes three Registered Nurses are responsible for monitoring and supporting the state’s school-based health centers and providing technical monito to assure that they are providing quality, culturally relevant health care services in accordance with the state’s administrative code; a data/grant manager; and an administrative assistant. In addition, IL Title V includes a Centers for Disease Control and Prevention (CDC) MCH Epidemiology Assignee, Amanda Bennett, PhD, MPH. Dr. Bennett has supported the program since 2014 and comes with a wealth of knowledge and expertise on data linkage and analysis, research methods, and program evaluation. Recently, IL Title V welcomed Cara J. Bergo, PhD as the Maternal Mortality Epidemiologist. Although Dr. Bergo’s position is primarily funded through a CDC grant, she provides her epidemiological expertise in addressing maternal morbidity and mortality in the State of Illinois which falls under one of IL Title V’s key priorities.

The IL Title V provides funding support for two Graduate Program Student Interns, a structured internship program operated out of the University of Illinois at Springfield. One intern supports school health data collection and analysis and the other intern supports the IDPH Office of Health Promotion’s Injury Prevention Program to work on adolescent suicide prevention and develop a state strategic plan around youth suicide.

The IL Title V also provides workforce development for those in the MCH field through: (1) the regional perinatal health APCs, which support perinatal and obstetric educators by assessing educational needs and providing continuing education; (2) the Illinois Women and Families Health Conference, which is an annual event organized by OWHFS to build the skills of health care and social service providers working with vulnerable families; and (3) the School Health Program, which provides ongoing technical assistance and support as well as structured training events to school nurses and school-based health centers.

For IL Title V staff, IDPH strongly encourages attendance as well as presentations at national and local conferences (e.g., AMCHP conference, CityMatch annual conference, American Public Health
Association [APHA] annual conference).

**CYSHCN**

UIC-DSCC uses Title V funds to support operation of the Core Program. The UIC-DSCC Senior Administration Team includes Thomas F. Jerkovitz, Executive Director; Molly W. Hofmann, Associate Director for Care Coordination; Kevin W. Steelman, Associate Director of Finance; and Andrew B. Nichols, Director of Information Technology.

UIC-DSCC maintains a Staff Development and Training Unit. This unit works with the QITs, Quality Champions, and other unit managers and employees to develop, distribute, and present staff training and development programs throughout the state. The unit maintains a Learning Management System (LMS) that is used to deliver training modules on topics related to care coordination, including new staff orientation; person-centered planning; administrative rules, policies, and procedures; basic training for new staff; child abuse and neglect; medical homes; critical incidents; and transition. Training is an essential strategy for achieving the goals in UIC-DSCC’s mission statement and strategic plan. Other workforce development activities include a nursing education program developed with Lurie Children’s Hospital, and the Transition Conference.

UIC-DSCC also works with many interns each year from the University’s College of Nursing and School of Social Work. The Illinois Department of Financial and Professional Regulation (IDPFR) has authorized UIC-DSCC to provide continuing education credits for nurses and social workers. This allows UIC-DSCC to support the ongoing education of its care coordination workforce and help them maintain their professional licensure.
III.E.2.b.ii. Family Partnership

*IL Title V*

OWHFS makes an intentional effort to engage and integrate consumers into the decision-making and program planning of Title V activities as it seeks to reach families across the life course and improve health outcomes. Currently, IL Title V partners with EverThrive Illinois to create the MCH Family Council which consists of 36 members arranged into seven regional groups. The members are recruited through regional public health offices, referrals from local health departments, and social service programs such as Healthy Start and WIC. EverThrive Illinois is responsible for recruiting, organizing, and guiding the MCH Family Council, as well as communicating council recommendations to the IL Title V.

The specific purpose of the MCH Family Council is to provide feedback and recommendations related to Illinois’ MCH programming and perspective on critical consumer issues covering MCH issues across the lifespan. The Council is asked to provide feedback at the individual, community, and policy levels. Feedback and recommendations received thus far have covered topics such as open enrollment, Medicaid managed care, Immunizations, the opioid epidemic, and perinatal regionalization (levels of care for birthing hospitals). When assessing MCH needs for FY20, the Family Council provided feedback regarding several key areas. In the area of Infant Health, council members expressed a need for information and resources related to safe sleep and the proper use of car seats. In the area of Child Health, the Council stated that timely receipt of services for identified developmental issues was of concern. In addition, the council discussed, at length, issues related to the state’s health and social service systems which impact health care access, quality, and ultimately the health of women, children, and families in Illinois. These issues included: inadequate numbers of pediatric providers, particularly specialists for CYSHCN’s who take Medicaid; continuity of care and inconsistent coverage of medications due to changes in managed care organizations (MCO); changes in MCO provider without notification to participants; not being able to go to a particular hospital because of the type of MCO provider the patient has. While the IL Title V does not have the authority over many of the system problems and questions that have been raised during the Council’s discussions, Title V can leverage its relationships within IDPH to provide leadership and increase the visibility of these issues to promote an inter-agency governmental response advancing a system of care for women, infants, children, and families.

IL Title V and EverThrive Illinois continue to stress the importance of consumer engagement and include more individuals and families in the process. EverThrive has taken steps to remove barriers to MCH Family Council participation and to compensate members for their time and the valuable input they provide. MCH Family Council members receive a $30 consulting fee per quarterly meeting. The meetings also provide food and transportation as necessary. Participants can bring their children to the meetings and meetings are intentionally scheduled at locations with child-friendly areas, so the mothers can both participate and keep an eye on their children playing. Family Council members are also provided professional development opportunities as well as strongly encouraged to attend the Illinois Women and Families Health Conference. For FY21, IL Title V seeks to further engage consumer by establishing a process by which Family Council members participate in grantee quarterly meetings and Title V staff annual program planning meetings.

*CYSHCN*

The Family Advisory Council (FAC) is the primary structure for family engagement in the CYSHCN program. At full membership, the council has representation from each UIC-DSCC Region. The FAC is actively engaged in developing and interpreting the family survey conducted for the Block Grant needs assessment.
UIC-DSCC employs two (one full-time and one half-time) Family Liaison Specialists. They, along with regional staff, participate in numerous outreach and provider education events, provide staff support for the Family Advisory Council, and organize UIC-DSCC’s annual Institute for Parents of Preschool-aged Children who are Deaf or Hard of Hearing.

UIC-DSCC has a family-friendly website that includes information about UIC-DSCC services, upcoming events, news, and information about medical homes, adolescent transition, family partnership, and other aspects of services for CYSHCN. UIC-DSCC also has a presence on Facebook to promote events of interest to families and to provide information on medical homes and adolescent transition. UIC-DSCC operates a toll-free telephone line, 1-800-322-3722 (800-322-DSCC).

III.E.2.b.iii. States Systems Development Initiative and Other MCH Data Capacity Efforts

IL Title V

The IL Title V places a strong emphasis on improving data capacity and infrastructure to support maternal and child health (MCH) programs. Because of the 2020 Title V Needs Assessment, Illinois chose to select a state MCH priority centered on data for 2021-2025. This priority demonstrates the ongoing commitment of the IL Title V to ensuring evidence-based practice and data-driven decision-making.

State Systems Development Initiative (SSDI)

For the 2018-2022 SSDI application, Illinois developed a plan to support staff development, analytic activities, data linkage, and data system enhancement. Three specific goals are being pursued through the Illinois SSDI project:

1. **Build and expand state MCH data capacity to support the Title V MCH Block Grant program activities and contribute to data-driven decision making in MCH programs, including assessment, planning, implementation, and evaluation.**

Over the last several years, the IL Title V has built up its ability to access population-based data sets and calculate key measures of MCH. The majority of the key MCH data files are housed by other IDPH offices, and not under the direct authority of the OWHFS or the IL Title V. This required OWHFS to set up intra-agency data sharing agreements or memoranda to allow Title V to access and analyze critical population-based data. OWHFS has successfully developed agreements or mechanisms that allow direct, ongoing access to the following data files:

- Birth, death, and fetal death certificates (including provisional files)
- Hospital discharge records (both inpatient and outpatient) for women and children
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Behavioral Risk Factor Surveillance System (BRFSS)
- Cornerstone (data system for DHS programs, such as WIC and case management)

The IL Title V also benefits from the availability of other public data files, such as the Youth Risk Behavior Survey (YRBS), the National Survey of Children’s Health (NSCH), and the National Immunization Survey (NIS). Additionally, Title V has internal data systems that track information related to school health, maternal mortality, and the perinatal system. The availability of these data sources to OWHFS staff and to the University of Illinois at Chicago, Center of Excellence in Maternal and Child Health (UIC CoE-MCH) partners enables the assessment of a wide assortment of MCH topics and supports the broad priorities of the IL Title V.
Although IL Title V has had a long-lasting relationship with UIC CoE-MCH since 2014, participation in SSDI has allowed Title V to further leverage the relationship and expand its MCH analytic capacities. This partnership is memorialized in an intergovernmental agreement (IGA) which is in the process of being renewed through 2021. Through this IGA, Illinois Title V will continue to obtain technical assistance from UIC MCH epidemiology faculty, staff, and students in the areas of strategic planning, measurement strategy, data analysis, and data product development.

2. **Advance the development and utilization of linked information systems between key MCH datasets in the state**

Linkage of data systems has long been identified as a need to improve MCH surveillance, assessment, and evaluation, but few of the Illinois MCH datasets are currently linked. The Title V epidemiology team continues to advance the development and use of linked MCH data systems through ongoing evaluation and validation. For example, the CDC MCH Epidemiology assignee conducts validation of the matched infant birth and death certificates each year as the vital records files are finalized. Updated information is provided to the IDPH Division of Vital Records so they can improve their matching processes. For the 204-2016 birth cohorts, this validation of the linkage process improved the matching rate for resident infant deaths from about 90% to about 99%. This will be an annual ongoing activity of the Title V data team to ensure that high-quality matched infant birth and death records are available for detailed analyses of infant mortality.

During FY18, the IL Title V obtained identifiable hospital discharge data for women and infants to link to other MCH datasets. OWHFS will continue to build trust and collaboration with the discharge data steward (IDPH Division of Patient Safety and Quality) to demonstrate the value of the data linkages and to assure the security and appropriate use of the data. During FY2018, Title V epidemiology staff developed a standardized algorithm and began the process of linking infant hospitalization records to birth certificates for the 2015 and 2016 birth cohorts. This linkage will continue to be finalized and tested during FY2019. Additionally, the addition of maternal hospitalization records to the linked files will be completed during FY2019 and FY2020.

3. **Provide data support to state quality improvement activities.**

Illinois Title V is involved in many quality improvement (QI) activities across various MCH topics and programs. Data staff support these QI initiatives through study planning, data collection, data analysis, and interpreting/translating data to support QI work. This includes supporting the data collection, analysis, and interpretation needs of the state Collaborative Improvement and Innovation Networks (CoIIN) to Reduce Infant Mortality, providing technical assistance to the Illinois Perinatal Quality Collaborative, and funding the development and maintenance of the ePeriNet data system, which collects information on key maternal and neonatal outcomes from birth hospitals and APCs. During FY2018, the CSTE Fellow conducted an evaluation of the infant and maternal transport forms in ePeriNet to consider how to improve the system’s functions as a surveillance system of sentinel perinatal events.

A plan is being developed for how to improve this system based on the evaluation recommendations. The IL Title V places a strong emphasis on improving data capacity and infrastructure to support maternal and child health (MCH) programs. Because of the 2015 Title V Needs Assessment, Illinois chose to select a state MCH priority centered on data for 2016-2020: “Strengthen the capacity for data collection, linkage, analysis, and dissemination; Improve MCH data systems and infrastructure.” The decision to have a priority specifically focused on data systems and infrastructure arose from the ongoing commitment of the IL Title V to ensuring evidence-based practice and data-driven decision-making. More information about this priority is available in the State Action Plan Table and corresponding narrative for the annual report and application year. The state action plan for this priority covers four broad goals that are strongly tied to the SSDI goals and objectives, including: enhancing
staff capacity, improving data infrastructure and systems, increasing epidemiologic production and use, and forging partnerships that improve data capacity and infrastructure. More information about specific activities related to these four data goals is available in the State Action Plan for the Cross-Cutting Domain.

Other MCH Data Capacity Efforts

Illinois has a robust system of identifying and reviewing maternal deaths, including two multi-disciplinary review committees for clinical and violent deaths. The review committee recommendations are often connected to QI initiatives at the hospital, regional, and state levels. The Title V data staff have supported these changes to the committee and have provided ongoing data collection and analysis of the case review and vital records data. In fall 2017, staff began working with the state information technology (IT) office to implement the Maternal Mortality Review Information Application (MMRIA) (developed by the CDC), and this system was made available for us in January 2019. Overall, IDPH is currently undertaking an agency-wide effort to increase the ease of internal data sharing between offices by implementing standard data request forms that eliminate the needs for individualized legal agreements for data sharing between offices. In the future, this may facilitate data sharing and allow Title V to obtain access to other IDPH datasets.

CYSHCN

UIC-DSCC is committed to continuous quality improvement and recognizes its integral role to the development and implementation of the comprehensive assessment and person-centered approach to care planning. UIC-DSCC’s Care Coordination leadership identifies performance measures, establishes targets, and leads the process for data collection, reporting, analysis, and application to improve the quality of care coordination services. UIC DSCC’s Quality Improvement Teams (QITs) are responsible for managing the quality improvement process and training regional staff to lead quality improvement efforts.

Performance data is reported through organizational scorecards that are supplemented by two other quality improvement strategies. The first supplemental strategy entails the QITs reviewing records to examine the quality and appropriateness of care coordination services provided to participants. The second strategy involves surveying families to assess their satisfaction with care coordination services. Brief questionnaires are distributed after select events (e.g., home visits), various intervals of program participation (e.g., one year after enrollment), at key milestones (such as reaching transition age), and at program exit.

In FY2019, UIC-DSCC implemented EccoVia Inc.’s (Eccovia Solutions’) ClientTrack software to support person-centered planning and care coordination. The system guides workflows, provides smart notifications and alerts, integrates health care data sources, and allows families to connect with their child’s providers.

In addition to Eccovia Solutions, UIC-DSCC developed a warehouse of care coordination and financial management data. Data is displayed in dashboards that summarize and present information for quick views. Current dashboards provide information on enrollment and caseloads.

III.E.2.b.iv. Health Care Delivery System

IL Title V

Illinois’ health care delivery system is multi-faceted and has a number of programs and initiatives. The Illinois Department of Healthcare and Family Services (HFS) is Illinois’ largest insurer. It administers
the All Kids medical assistance program. This program is jointly financed by state and federal funds and provides critical health care coverage to Illinois' most vulnerable populations.

In 2011, Illinois enacted significant health care reform including the Saving Medicaid Access and Resources Together (SMART) Act (Public Act 97-0689). The Act contained approximately 62 items, one of which established the goal of enrolling at least 50% of all Medicaid beneficiaries in a "care coordination," or managed care, plan by January 1, 2015. This has led to a rapid expansion of Medicaid managed care within the state. Currently, five managed care plans are serving the “Family Health” population (children, pregnant women, and childless adults eligible for Medicaid under the Affordable Care Act) statewide and two more plans are serving beneficiaries in Cook County.

Effective July 2018, the Centers for Medicare & Medicaid Services (CMS) approved an 1115 demonstration project, the Illinois Behavioral Health Transformation. According to HFA, a key aim of the project is to, “building a nation-leading behavioral health strategy will help turn the tide of the opioid epidemic, reduce violent crime and violent encounters with police, and improve maternal and child health.” Ten pilots were implemented through the demonstration including Substance Use Disorder Case Management, Peer Recovery Support Services, Evidence-Based Home Visitation for children born dependent on opioids, and Supportive Employment Services. It is expected that the behavioral health transformation will have a significant impact on the State over the next 5 years by touching all regions of the state, improving care for approximately 800K Medicaid members with behavioral health conditions, builds a delivery system focused on integrated physical and behavioral healthcare impacting all 3.2M Medicaid members (and lays the foundation for a more integrated system for all 13M Illinoisans), and utilize the $2.7 Billion in federal match for Medicaid services.

In 2017, HFS convened a workgroup to design an Integrated Health Home model for the State of Illinois. This is an outcome-based initiative that incorporates non-medical interventions and will help to increase the likelihood of successful pregnancies, Shannon Lightner, the Deputy Director of OWHFS, was part of the workgroup and represented the IL Title V and public health issues at large. The Integrated Health Homes model was projected to launch in early 2020, along with a quality incentive program for managed care organizations to increase the number of women who can deliver full-term babies. Unfortunately, due to the COVID-19 Pandemic, the launch was delayed until early 2021.

Illinois’ IL Title V and HFS have agreed, through an interagency agreement (IGA), to partner and collaborate to improve the health status of Illinois’ women, infants, and children, including children with special health care needs, by sharing data and assuring the provision of preventive services, health examinations, necessary treatment, support, and follow-up care permitted under the Social Security Administration (SSA) and enumerated in each program’s respective state plans. The agencies agree that by partnering they can enhance their data capabilities, maximize the utilization of care, increase program effectiveness and protect against the duplication of efforts, expenditures and resource allocation. In addition, the partnership further promotes the continuity of care, sharing and leveraging of expertise, and greater accountability within and amongst the agencies.

HFS has also agreed to provide IDPH staff access to Medicaid data regarding maternal mortality cases. This ensures that for every case where the decedent was a Medicaid beneficiary, IDPH can have a full understanding of all her health encounters, providing for a more thorough case review. The arrangement is beneficial to the MMRC and MMRC-V in their review of cases and subsequent recommendations to Title V to improve Maternal health outcomes.

**CYSHCN**

Most CYSHCN eligible for Medicaid will be required to enroll in one of five managed care plans
beginning November 1, 2019. Additionally, according to Illinois law, children who receive in-home shift nursing services, as well as medically fragile and technology dependent children who are eligible for the home and community-based services waiver cannot be mandated to enrollment in a managed care plan. To continue to strengthen the relationship between Title V and Title XIX agencies, senior UIC-DSCC staff are communicating regularly with HFS leadership. It is important to build a positive rapport and maintain open communication because both agencies have a vested interest in the various programs affecting CYSHCN.
III.E.2.c State Action Plan Narrative by Domain

FY2019 IL Title V State Annual Report by Domain

Women/Maternal Health - Annual Report

Illinois’ Title V priority for the Women and Maternal Health Domain is:

- Assure accessibility, availability, and quality of preventive and primary care for all women, particularly for women of reproductive age (Priority #1)

There are some concerning trends for the health of Illinois’ women and mothers. In recent years, the maternal mortality and severe maternal morbidity rates have worsened slightly and show large racial disparities. In Illinois, non-Hispanic black mothers are about twice as likely to experience a severe maternal morbidity and more than three times as likely to die as non-Hispanic white mothers (National Outcome Measure [NOM] #3, NOM #2). Building on improvements over the last several years, the teen birth rate in Illinois continues to fall to an all-time low (NOM #23).

Illinois women continue to succeed in accessing important health care services; however, some areas of health care services are inaccessible to many women.

For FY2019, the selected NPMs and SPM remained relevant and there was no need to change them. However, for the FY2020 Application, revisions were made to Evidence-based Strategy Measure (ESM)-1.1. The ESM was slightly edited to align with available measurement mechanisms. Specifically, ESM 1.1 was previously defined as the “number of website hits to the Healthy Choices, Healthy Futures Perinatal Education Toolkit”, but limitations in the available data analytics for the hosting website precluded Title V from obtaining this number. The ESM 1.1 was edited to count the number of individuals receiving information on the toolkit through events and meetings over the course of the year, thus tracking the dissemination of the toolkit through the efforts of EverThrive Illinois beginning FY2019.

The IL Title V utilized the following strategies to address the Women and Maternal Health Domain priority:

A. Support dissemination of the Illinois Healthy Choices, Healthy Futures Perinatal Education Toolkit, which includes resources about pre-/inter-conception health and the transition to postpartum care.

In collaboration with EverThrive Illinois, IL Title V supports the ongoing enhancement, dissemination and tracking of the Illinois Healthy Choices, Healthy Futures Perinatal Education Toolkit. The toolkit was initially created by the Child Health Insurance Program Re-Authorization Act (CHIPRA) Quality Demonstration Grant workgroup to provide patient-focused information on preconception, prenatal, postpartum, and inter-conception health topics, provider-focused information on postpartum care transition strategies, a prenatal care quality assurance tool, and a high-risk referral crosswalk, developed by the American Congress of Obstetricians and Gynecologists (ACOG) and the Illinois Academy of Family Physicians (IAFP). The toolkit is accessible via a website maintained by EverThrive Illinois: http://healthychoiceshealthyfutures.org/. The primary audience for the toolkit is perinatal health providers.

During FY2019, EverThrive Illinois hosted, updated, and promoted the Healthy Choices, Healthy Lifestyles Perinatal Education Toolkit. More specifically, EverThrive engaged social service providers in providing direct feedback on the tool to ensure the relevance and accessibility of the Perinatal Education Toolkit. Home visitors, doulas, and case managers and other key stakeholders were convened to
participate in focus groups. This activity led to a comprehensive update and re-organization of the toolkit to reflect the needs of this primary audience. According to EverThrive’s data, the toolkit received over 500 views within the first 6 months of FY2019.

**B. Partner with the Illinois Department of Corrections and two state women’s correctional centers to support ongoing health promotion activities for incarcerated women (including health education programs and lactation support) and prison staff training.**

During FY19, Illinois Division of Population Health Management (DPHM), which is a division of OWHFS, continued its collaboration with the Illinois Department of Corrections (IDOC). Illinois is home to three women’s correctional facilities, Logan Correctional Center (LCC), Decatur Correctional Center (DCC) and Fox Valley Adult Transition Center (ATC). Combined, these facilities house more than 2,500 women. There are a total of eight Mom and Baby joint housing units at the facilities.

DPHM has been able to establish a strong partnership with IDOC which allows DPHM to provide education and support to pregnant women and new mothers and infants housed within two of the facilities (LCC and DCC). The education and support consist of pregnancy education, breastfeeding education, and lactation support and counseling. The healthcare staff receives prenatal and delivery education as well.

DPHM also partners with outside agencies to provide support the women’s needs once a baby is delivered. A partnership with the Illinois Department of Children and Family Services (DCFS) assists in identifying appropriate parenting education curriculum. Another key partnership is the collaboration with the Women, Infants, and Children (WIC) program. This partnership helps to ensure that the women and babies are receiving the needed care through the services available while residing in IDOC.

There were several noteworthy activities during FY2019. OWHFS partnered with IDOC to open the Pregnancy Wing at LCC in March 2019. This wing houses all pregnant women in the facility in one location. In addition, DPHM provided the facilities with new breast pumps, pumping kits, milk storage bags, and breast pads. Secondly, it strengthened its partnership with the Baby Talk Program to provide enhanced educational services for new mothers and babies up to three years old who resided at DCC. Lastly, it encouraged and supported internal staff development. One of DPHM’s health educators became a Certified Lactation Counselor to better assist the women and babies during and after their pregnancy.

OWHFS and Title V leveraged the expertise of the regional Administrative Perinatal Center (APC) to provide additional trainings at both facilities. Specifically, four healthcare trainings were conducted between both facilities with approximately fifty staff being trained. The healthcare training team of the regional APC as well as the Maternal & Fetal Medicine (MFM) Physician have participated in the trainings. Establishing this relationship is important because it allows the MFM to meet with the women in their home setting prior to any office visits and address questions as well as identify anyone who may be experiencing a high-risk pregnancy. These interactions occur during the healthcare trainings and is part of a Q&A with all of the pregnant women present.

OWHFS’ work with IDOC is also supported by Title V’s perinatal nurse located downstate. During FY19, she attended hospital meetings discussing the care of women from the correctional centers and how perinatal regionalized care transports improve maternal and neonatal outcomes. The Title V perinatal nurse collaborated with the regional APC Network Administrator and the maternal-fetal medicine physician APC co-director to draft plans for health education programming for both centers. The Title V perinatal nurse collaborated with other OWHFS staff and proposed the educational plan for health programming to the administration of the LCC. Obstetrical and neonatal simulation training was provided on multiple occasions at the LCC to nurses, mid-level providers, nursing administration, and a physician. Based on the positive feedback from staff, obstetrical and neonatal simulation training was also provided
on multiple days at the DCC. The Logan Correctional Center agreed to an unannounced simulation for staff which occurred in July 2019. This simulation allowed for staff to test their obstetrical and neonatal skills and allowed them the opportunity to debrief afterwards to identify other opportunities to improve the quality of care for pregnant women.

C. Identify pregnancy-associated deaths and facilitate two state Maternal Mortality Review Committees (one focused on pregnancy-related deaths and one focused on violent deaths)

Illinois was one of the first states to implement maternal mortality review and created the state Maternal Mortality Review Committee (MMRC) in 2000. Additionally, a second state committee, the Maternal Mortality Review Committee on Violent Deaths (MMRC-V) was formed in 2015 to review deaths of women who died within a year of pregnancy due to homicide, suicide, or drug overdose. These committees are structured as sub-committees of the state’s Perinatal Advisory Committee, with the purpose of providing expert recommendations to IDPH on how to improve maternal and infant health. Since 2002, Illinois has followed the CDC recommendation to identify all pregnancy-associated deaths. Illinois uses multiple methods simultaneously to ensure pregnancy-associated deaths are accurately identified and counted each year. First, the state database of death certificates is used to identify deaths that may be pregnancy associated. There is a checkbox on the death certificate that indicates whether a woman was pregnant at the time of death or pregnant within the last year.

Some cause of death codes indicate that a death may have been related to pregnancy. Death certificates for any woman age 15 to 50 years are also checked against the databases of birth certificates and fetal death certificates to look for matching information. If there is a birth or fetal death record in the twelve months prior to a woman’s death, her death is flagged as a pregnancy-associated death. In addition to the state data systems, there are other ways that maternal deaths are identified in Illinois. All Illinois hospitals are required by the State to report any known pregnancy-associated deaths to IDPH within 24 hours. In addition, IDPH completes regular searches of major newspapers throughout Illinois to identify articles or obituaries that indicate the death of a woman while pregnant or within one year of pregnancy. For example, if an obituary mentions that a deceased woman has a surviving child who is less than one year old, the woman’s case is flagged as a potential pregnancy-associated death. Once the list of potential cases is complete, IDPH contacts the hospitals and health centers where the women received care to request records from the time of her most recent pregnancy to her death. These medical records provide details about the woman’s death and her medical history. For instance, records are routinely requested from the hospital where the woman died, the hospital where she gave birth, and the physician office or health center where she received prenatal care. When relevant, records are also requested from police departments, sheriff’s offices, and medical examiner or coroner’s offices. IDPH is constantly reviewing records to identify additional hospitals or health care providers that may be able to send more records that provide information on the case. Hospitals and medical providers are required to provide copies of all medical records related to maternal deaths within 30 days of IDPH’s request. IDPH compiles this information to confirm and accurately track the number of pregnancy-associated deaths in Illinois each year.

Though information from death certificates and other public health records may help identify counts of maternal deaths, these records cannot determine the preventability of cases or the factors involved in the case. The CDC recommends review of maternal deaths by a multidisciplinary committee as a means of gathering additional information about how the woman died, whether the death was preventable, and opportunities for preventing future maternal deaths.

During 2017, IDPH implemented a new review process to align with best practices promoted by the CDC. The goal was to improve several key components of the review process, including standardizing case abstraction, increasing review efficiency through structured meeting facilitation, and shifting to a population-health focus (instead of a purely clinical emphasis) to also consider how
social and non-medical factors that may have contributed to a death. Overall, IDPH saw a need for more structured administrative and technical support to the committees, especially in terms of chart abstraction and data analysis. As a result, IDPH committed to taking a more active role in supporting the committee meetings, participating in reviews, and collecting and analyzing data. To align with national work, Illinois adopted the use of standard CDC data collection forms and resources. This ensured that the data collected by the Illinois MMRC and MMRC-V would be consistent with each other and with other review committees across the country.

During 2019, Illinois continued to implement the maternal mortality review process for deaths potentially related to pregnancy. From October 2018-September 2019, the MMRC held 5 meetings during 2019 and reviewed 27 cases, and the MMRC-V held 2 meetings and reviewed 25 cases. IDPH completed its report of the cases reviewed during FY18 and published its first-ever maternal morbidity and mortality report in October 2018. The report disseminated information about adverse maternal outcomes and outlined specific recommendations for prevention. A press conference was held to publicize the report in October 2018. There was much interest in the findings and recommendations of the report. Numerous state legislation passed during the 2019 Legislative Session included the following:

- **PA 101-0038 – Task Force on Infant and Maternal Mortality Among African Americans.** This act creates the Task Force on Infant and Maternal Mortality Among African Americans Act. The task force, under the purview of the IDPH, is charged with establishing best practices to decrease infant and maternal mortality among African Americans in Illinois. The task force is to be comprised of various healthcare professionals and associations representing healthcare professionals, as well as a hospital administrator. The task force is to meet quarterly to review data and research to better understand the causes of high infant and maternal mortality among this population and produce an annual report to the General Assembly detailing its findings and any recommendations.

- **PA 101-0091 – Maternal Blood Pressure Equipment.** This act, effective Jan. 1, 2020 requires hospitals to have proper instruments available for taking a pregnant woman’s blood pressure.

- **PA 101-0386 – Maternal Mental Health Insurance Coverage.** This act requires insurance coverage for mental health conditions that occur during pregnancy or during the postpartum period.

- **PA 101-0390 – Hospital Hemorrhage Training.** Effective Jan. 1, 2020, this law requires all birthing facilities, defined as a hospital with at least one obstetric or neonatal intensive care bed, to conduct annual continuing education for providers and staff of obstetric medicine and emergency departments that may care for pregnant or postpartum women. This education must include management of severe maternal hypertension and obstetric hemorrhage. Applicable hospitals must demonstrate compliance with these education and training requirements. Additionally, IDPH is required to “support” the Illinois Perinatal Quality Collaborative (ILPQC) to improve birth equity and reduce peripartum racial and ethnic disparities. The initiative is to include the development of best practices for implicit bias training and education in cultural competency to be used by birthing facilities in interactions between patients and providers. Finally, IDPH’s Maternal Mortality Review Committee is to make available to all birthing facilities best practices for timely identification of all pregnant and postpartum women in the emergency department for appropriate and timely consultation with an obstetric provider. Applicable hospitals must update their policies to ensure they are identifying pregnant and postpartum women seeking care in their emergency departments. Hospitals may use telemedicine to meet this consultation requirement.

- **PA 101-0445 - Pregnancy and Childbirth Rights.** This law, effective Jan. 1, 2020, amends the
Medical Patient Rights Act by setting forth certain rights that women have with regard to pregnancy and childbirth. The 19 rights outlined include appropriate access to care prior to, during and after the pregnancy, choice in the type of provider for her maternity care professional and the setting in which she receives her care. Healthcare providers, including hospitals, are required to post information about these rights in a prominent place in their facilities and on their websites.

- **PA 101-0446** – Reporting of Infant and Maternal Mortality. These changes to the Hospital Report Card Act adds the following information that hospitals must submit as part of their quarterly reports to IDPH: (1) Each instance of preterm birth and infant mortality within the reporting period, including the racial and ethnic information of the mothers of those infants; and (2) Each instance of maternal mortality within the reporting period, including the racial and ethnic information of those mothers.

- **PA 101-0447** – Maternal Levels of Care. This act requires IDPH to establish levels of maternal care for hospitals in Illinois. These levels of care are to be complimentary but distinct from the perinatal levels of care system. IDPH, by rule, will develop criteria for the designation of hospitals based on their capabilities. The department will also collect additional data on maternal mortality and morbidity to lead any future changes to the maternal levels of care.

- **PA 101-0512** – Maternal Mental Health Education. This creates the Maternal Mental Health Conditions Education, Early Diagnosis, and Treatment Act. Effective Jan. 1, 2020, this act requires that the Department of Human Services (DHS) to develop educational materials on maternal mental health conditions, and make them available to birthing hospitals, defined as those hospitals with licensed obstetric beds. Starting Jan. 1, 2021, applicable hospitals must distribute those materials to employees regularly working with pregnant or postpartum women, as well as supplement those materials with information and resources relevant to their facility or region. Similar requirements currently exist in the Perinatal Mental Health Disorders Prevention and Treatment Act. Hospitals should review their policies to see how they can simultaneously comply with both requirements.

- **PA 101-0390** - IDPH must support ILPQC efforts to implement an initiative to improve birth equity and address peripartum racial and ethnic disparities.

- **PA 101-0390** - IDPH, in consultation with the MMRC, shall make available to all birthing facilities best practices for timely identification of all pregnant and postpartum women in the emergency department and for appropriate and timely consultation of an OB provider to provide input on management and follow-up.

- **Budget passed with language extending Medicaid eligibility.**

A second maternal morbidity and mortality report is scheduled for release in FY21.

In FY2019, IDPH pursued grant opportunities and partnerships that would enhance its efforts to improve maternal health and reduce maternal mortality in Illinois. IDPH successfully applied for a CDC Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE-MM) Grant. This grant supports IDPH’s efforts to support and manage the MMRCs. In addition, IDPH partnered with the UIC CoE-MCH on its HRSA Maternal Health Innovation Grant. IDPH is serving as a co-lead and the Title V Director is co-chairing the IL Maternal Health Task Force. Finally, IDPH has a key role on the Merck for Mothers Grant with EverThrive Illinois and the Alliance (a network of FQHCs). This grant seeks to improve prenatal care provided at FQHCs.
D. Conduct reviews of severe maternal morbidities (SMM) through the regional administrative perinatal centers and convene statewide SMM review sub-committee to develop recommendations for improving local reviews of SMM.

According to the Centers for Disease Control and Prevention, severe maternal morbidity (SMM) has increased over 200% between 1993 and 2014. In collaboration with the 10 Illinois Administrative Perinatal Centers and the UIC Center for Research on Women and Gender, Illinois began the Severe Maternal Morbidity (SMM) Surveillance and Review Project during 2017. In this project, all Illinois obstetrical hospitals identify and report on SMM cases, defined as a pregnant or postpartum (up to 42 days) woman who was admitted to an intensive care unit (ICU) and/or transfused with four or more units of packed red blood cells. The UIC Center for Research on Women and Gender (UIC-CRWG) developed a standardized SMM Review form in partnership with the APCs, which is being used by hospitals and APCs to collect more information on the circumstances surrounding SMM events, preventability, and opportunities for intervention. APCs are reporting the SMM Review forms into the ePeriNet database, which will allow for population-based analysis of SMM over time.

The UIC-CRWG provides in-depth technical assistance to the hospitals and APCs as they conduct reviews and evaluate the quality of the data reporting into ePeriNet. Monthly data quality reports are sent by UIC-CRWG to each APC administrator to support local review processes and to inform changes to the review form and ePeriNet data collection system. The UIC- CRWG team presented on project progress at five APCs and a joint meeting of the APC co-directors during the reporting period. The UIC team also creates an annual report for IDPH that summarizes the data.

E. Participate in ASTHO Long-Acting Reversible Contraceptives (LARC) State Learning Collaborative and advise state family planning program and contraceptive initiatives.

Although the ASTHO Long-Acting Reversible Contraceptives LARC Learning Collaborative ended in FY18, Illinois will continue to work to increase education and support of health care providers and patients around the use of LARC. This includes working with the Illinois Department of Corrections to incorporate family planning into the two women’s prisons to offer family planning services to women prior to release, collaborating to expand the efforts of ILPQC’s immediate postpartum LARC initiative and integrating the Title X Family Planning Program with school-based health centers.

F. Collaborate with IDPH Division of Oral Health to convene stakeholders and develop a statewide strategic plan and resource manual for oral health during pregnancy and early childhood (same as strategy #3-C).

IL Title V and the Division of Oral Health recognize that oral health is an essential component to improving the overall health for the women, children and families across Illinois. Anticipatory guidance, education, and risk-based care is routinely provided within the prenatal and primary care provider health care system. The Illinois Oral Health During Pregnancy and Early Childhood Project focused on the development of the Oral Health During Pregnancy and Early Childhood in Illinois resource manual. The resource manual presents actionable activities that encourage adoption of an oral health focus within the health care environment. This focus supports prenatal and primary care providers to educate, assess, and refer patients for oral health issues.

With a patient-focused and systems-oriented approach, prenatal and primary care providers can easily implement the field-tested oral health integration concepts provided in the resource manual. Oral Health During Pregnancy and Early Childhood in Illinois is divided into three main sections addressing educational information. The sections are: “General Information”, “Oral Health Practice Guidelines for Pre- and Perinatal Women”, and “Early Childhood and Families with Young Children”.
Further subsections detail strategies to implement for in-office system change. The appendices, inserts, and resources provide additional information aimed at improving health literacy, encouraging routine self-care practices, promoting prevention activities, and addressing access to treatment services. To promote a change within inter-disciplinary systems, the *Oral Health During Pregnancy and Early Childhood in Illinois* resource manual establishes a care coordination protocol to close the communication loop between providers. The protocol includes a referral form for use by health care/support services providers to initiate a referral to an oral health care provider. To close the communication loop, the oral health provider completes the oral health section of the referral form and returns it to the referring provider. By using these forms, the communications between providers are standardized and coordinated.

Once the packaging of the manual is finalized, it will be distributed to and through local, regional, and statewide conferences, provider networks, local health departments, the IDPH website, and community health and wellness meetings.

G. **Lead CoIIN- Social Determinants of Health workgroup to assess, quantify, and describe the impact that childcare has on prenatal, intrapartum, and postpartum care in Illinois and develop optional strategies and approaches that could be implemented in clinic and hospital settings to address childcare.**

The iteration of the CoIIN-Social Determinants of Health workgroup focusing on childcare began in Fall 2017. Through focus groups and informal discussion with health care providers, the Illinois CoIIN team identified childcare, or lack thereof, during pregnancy, childbirth, and postpartum as a non-traditional social determinant of health that may negatively impact health outcomes for the mother and her baby.

In informal discussions with Illinois’ birthing hospitals we learned that the lack of child care during pregnancy, at childbirth, and in the postpartum period is not only a barrier to timely access to health care, but has resulted in poor outcomes including the death of a mother, who while very ill, refused to go to the emergency department because she had no one to watch her new baby and another mother who miscarried because she left the hospital, against medical advice, to get home to other children who were unsupervised.

In the past, the lack of childcare has never been quantified. To begin to tackle this issue and make the case for changes in policy/procedures at the local, community, and state levels, the Illinois CoIIN team developed a three-pronged approach to collect data which consisted of surveying birthing hospitals, surveying Federally Qualified Health Centers (FQHCs), and interviewing Healthy Start clients.

In FY2019, the workgroup had great success in partnering with hospitals and local community health centers. The survey was disseminated a total of 98 hospitals and 44 FQHCs complete the survey. After reviewing the data from the completed survey, the workgroup explored the process for field testing questions it could potentially add to the state’s PRAMS project. Surveying postpartum women would add an individuals’ perspective to the need for emergency childcare in the prenatal, labor/delivery and postpartum periods. Approaching this systematically would enhance the PRAMS surveillance system in Illinois and potentially other states. The workgroup plans to draft and submit a formal field-testing report to the CDC so that the selected questions can be reviewed and hopefully added to the bank of questions from which state PRAMS projects can choose.

The workgroup activities have helped to strengthen IL Title V’s relationships with the Healthy Start Programs across Illinois. The team developed seven questions to survey among postpartum Healthy Start participants to gain insight on childcare related issues among postpartum women. A total of 29 women completed the surveyed. It is expected that another 15 women will complete the survey by the end of the calendar year. These women, however, will not necessarily represent Healthy Start participants.
For FY2019, one other notable activity was securing a Title V summer intern and two masters level interns over the summer. These interns help to write up preliminary results on the hospital and FQHC surveys and conducted a literature review. One of the interns, will continue at IDPH beyond the summer and will assist in developing a policy/status brief on emergency childcare in Illinois.

H. Participate in Partnership for Integrating Oral Health Care into Primary Care project with IDPH Division of Oral Health and a local health department to integrate the interprofessional oral health core clinical competencies into primary care practice, particularly for pregnant women and adolescents.

IL Title V, the IDPH Division of Oral Health, the Partnership for Integrating Oral Health Care into Primary Care project and the Champaign-Urbana Public Health Department (C-UPHD) coordinated to integrate the Health Resources and Services Administration’s interprofessional oral health core clinical competencies into primary care practice. This project will assist primary care health professionals and support staff at C-UPHD in conducting oral health risk assessments, screenings, preventive interventions, education, and interprofessional collaborative activities and, care coordination services, as applicable.

I. Establish well-woman care mini-grant program to assist local entities in assessing their community for need and barriers and developing a plan to increase well-woman visits among women ages 18-44.

To assist in addressing NPM #11, the IL Title V launched the Planning Grant to Increase Well-Woman Visits in Your Community Program. The overall goal of the program is to increase the percent of women ages 18-44 with a preventive medical visit (well-woman visits). To accomplish this goal, grant applicants must develop a plan to positively influence the number of women seeking well-woman care within their respective communities. More specifically, applicants must define and describe the community served, including barriers to accessing health care; identify locations in the community where women are seen for Well-Woman visits; and develop a plan to describe the increased well-woman care utilization in the community. The official launch of the program launches in FY20, but in the interim, OWHFS staff developed the notice of funding opportunity and began to make key stakeholders aware of the opportunity.

More information will be provided in the FY20 Annual Report when the program is officially launched.

J. Partner with UIC Center for Research on Women and Gender to implement a program at two clinic sites to expand the capacity of health care providers in the state of Illinois to screen, assess, refer, and treat pregnant and postpartum women for depression and related behavioral health disorders.

The University of Illinois at Chicago's Center for Research on Women and Gender received Title V funding in FY19 to implement a program at two clinic sites to expand the capacity of health care providers in the state of Illinois to screen, assess, refer, and treat pregnant and postpartum women for depression and related behavioral health disorders. The long-term goal of the project is to pilot a combination of strategies to increase the capacity of perinatal providers to screen, assess, refer, and treat behavioral health disorders, and to increase awareness of and access to affordable and culturally-appropriate services to improve the mental health and well-being of pregnant and postpartum women and their infants in the State of Illinois. The main objectives of this project are: 1) Provide in-person workshop training and resources on screening, diagnosis, and referral for maternal depression and related behavioral disorders to perinatal providers; 2) Provide real-time psychiatric consultation and care coordination for providers; 3) Screen women for depression,
anxiety, suicide risk, and substance use during the perinatal period using Computerized Adaptive Testing (CAT); 4) Increase access to depression prevention and treatment for medically underserved women using a telehealth intervention; 5) Increase access to substance use treatment for pregnant women; 6) Plan for scale-up and sustainability to implement the project components statewide.
Perinatal/Infant Health - Annual Report

Illinois’ priority for the Perinatal and Infant Health Domain is:

- Support healthy pregnancies and improve birth and infant outcomes (Priority #2)
- The selected NPMs, SPM and ESMs for the Perinatal/Infant Health Domain were still relevant and have not being changed.

The IL Title V utilized the following strategies to address the Infant and Perinatal Health Domain priority:

A. Maintain a strong system of regionalized perinatal care by supporting perinatal network administrators and outreach/education coordinators and identifying opportunities for improving the state system.

Illinois has two perinatal nurses (one northern region and one southern region) to cover all hospitals in Illinois that have perinatal units, approximately 120 facilities. The perinatal nurses work in conjunction with the 10 administrative perinatal centers. Each administrative perinatal center has one perinatal nurse administrator, two nurse educators, one maternal fetal medicine co-director, and one neonatology co-director. The administrative perinatal centers and the perinatal nurses perform site visits of the perinatal hospitals in Illinois to assess for compliance to the Illinois Perinatal Code 640.

The two perinatal nurses are fully funded by the IL Title V and function as nursing specialists in maternal, child, and adolescent health issues:

- Providing nursing expertise and leadership in the development, interpretation, and enforcement of regulations and program contract specifications related to programs impacting women throughout the reproductive cycle and infants working with other divisions at IDPH and external stakeholders such as the CDC and FDA to provide expertise and support for perinatal related needs
- Coordinating and monitoring assigned maternal and child health program activities
- Attending various state and local committee meetings (e.g., State’s Perinatal Advisory Committee) to identify opportunities for collaboration and alignment between programs
- Supporting hospitals statewide with education and technical assistance

I. Utilize the Levels of Care Assessment Tool (LOCATe) to describe neonatal and maternal levels of care and inform improvements to the regionalized perinatal system.

Implementation of the Levels of Care Assessment Tool (LOCATe) to capture information about the neonatal and obstetric personnel, services, and resources available at every birthing hospital in Illinois was completed in FY18. Title V will continue to encourage the use of the tool and will monitor and assess data going forward.

II. Conduct a study of very preterm infants (<32 weeks) delivered outside Level III facilities to identify reasons for no maternal or neonatal transport and barriers to risk-appropriate care.

Illinois has implemented a special data collection process to gather information on very preterm (VPT) infants born outside Level III hospitals. Since 2015, OWHFS have implemented a data collection tool with six major sections: infant characteristics, maternal characteristics, information about the hospital admission and stay, reasons why mother was not transported to a Level III before delivery, outcome of the infant, and reasons why infant was not transported to a Level III after delivery. All Illinois hospitals that
were not Level III facilities are required to complete the form for every instance of a live birth at 22-31 weeks gestation and to submit the form through the ePeriNet data system. These forms are linked to vital records files, enabling detailed analysis of patient characteristics and infant outcomes that are related to a lack of risk-appropriate care. Analysis of the very preterm review forms is ongoing in conjunction with the risk-appropriate care CoIIN workgroup.

Illinois will continue to collect the very preterm review form for all infants 22-31 weeks gestation born in non-Level III hospitals through the 2020 birth cohort. Data collection occurs through the ePeriNet online system. The Title V epidemiology team will continue to monitor form completion, follow-up on missing records, and analyze data to support the work of the risk-appropriate care CoIIN workgroup.

III. Convene Risk-Appropriate Care CoIIN workgroup to develop a quality improvement initiative to increase the percentage of very preterm infants (<32 weeks) delivered in Level III facilities.

In 2015, Illinois began a CoIIN workgroup focused on improving the percent of very preterm or very low birth weight infants receiving risk-appropriate care. The goal of the workgroup is to identify the barriers to risk-appropriate care and to develop quality improvement initiatives to overcome these barriers and ensure that more preterm infants are born in appropriate level hospitals.

This CoIIN team developed the concept for the very preterm review form and has worked closely with the Title V epidemiology team to interpret the data and develop evidence-based strategies. During 2018, the workgroup developed a grand rounds presentation that outlined some of the major findings and messages about risk-appropriate care. Analysis of risk-appropriate care data and the very preterm review forms is an ongoing process that is done in conjunction with the Risk-Appropriate Care CoIIN workgroup.

IV. Update state Obstetric Hemorrhage Toolkit based on information in the ACOG patient safety bundle and distribute updated materials to all Illinois hospitals.

The update of the hemorrhage toolkit was completed in FY18. The regionalized perinatal program will continue to disseminate the toolkit and other related training materials to birthing hospitals throughout Illinois. Hospitals will continue to be encouraged to provide annual training on obstetric hemorrhage to all hospital staff that interact with pregnant/postpartum women.

V. Designate and maintain perinatal levels of care and support administrative perinatal centers.

Illinois Perinatal Code 640 requires hospitals to have site visits done every three years. These visits include one perinatal nurse, one representative from the Perinatal Advisory Committee, and the administrative perinatal center team which includes one perinatal nurse administrator, one neonatal nurse educator, one obstetric nurse educator, one maternal fetal medicine director, and one neonatology director. The purpose for the perinatal site visit is to assess if a perinatal hospital is in compliance with the State’s Perinatal Code 640 according to the hospital’s designated level of care. Standards for perinatal care and resource requirements are reviewed for each hospital as related to the hospital’s perinatal level; the levels are I, II, II with Extended Neonatal Capabilities (II-E) and III.

The IDPH perinatal nurses also attend morbidity and mortality reviews at hospitals to keep abreast of emerging best practices and trends in the field. Quality improvement technical assistance site visits are also provided as requested. During FY19, the northern perinatal nurse attended 25 perinatal site visits, 20 morbidity and mortality reviews at the hospitals, and 18 quality improvement/assurance or technical assistance visits. The southern perinatal nurse attended 20 perinatal site visits, 17 morbidity and
mortality reviews at delivery hospitals, and 17 quality improvement/assurance or technical assistance visits.

Illinois has a regionalized perinatal health care program which provides the infrastructure and support for Illinois’ birthing and non-birthing hospitals. 10 highly resourced hospitals are contracted as Administrative Perinatal Centers (APCs) and charged with engaging and supporting a network of hospitals. Each birthing hospital had a perinatal level of care designation based on its resources and ability to care for neonates. The goal of the program is to improve birth outcomes through training, technical assistance, consultation on cases with complex health issues, and providing transportation to a higher level of care when appropriate. The IL Title V provides grants to the 10 APCs annually.

Below are FY19 highlights from the 10 APCs:

1. University of Chicago completed 50 severe maternal mortality reviews within network, including University of Chicago; all level III network hospitals including University of Chicago transitioned to instrument generation 4 HIV testing, and all network hospitals put in place discharge planning and early blood pressure checks for patients with preeclampsia or chronic hypertension.

2. Stroger Hospital is working collaboratively with the Chicago Department of Public Health (CDPH) who is a key partner with IL Title V. Stroger Hospital is participating in the Severe HTN Initiative collaborative which includes each network hospital demonstrating the integration of the HTN initiative into the process of providing care to the obstetrical patient presenting to the hospital for care; patients receiving scheduled 72 hour B/P checks prior to discharge from the facility; CDPH referrals for patients unable to return for follow up B/P checks; patients meeting the established criteria are discharged home wearing the Teal wristband; patients receiving their anti-hypertensive medication before leaving the unit; and severe HTN patients routinely reviewed internally and during the M&M conferences.

3. Northwestern performed a network needs assessment and identified additional education needs for Low-Risk Neonatal Certification prep (RNC-LRN) and High-Risk Neonatal Certification prep (RNC-NIC). Northwestern was able to utilize the IL Title V to offer both an RNC-LRN review course and an RNC-NIC review course for the network hospitals. Obtaining certification in neonatal nursing validate the nurses’ knowledge and allows nurses to demonstrate their specialty expertise.

4. University of Illinois at Chicago’s Perinatal Center is working with the University of Illinois (UI) Health Department of Psychiatry collaborated to implement a computer-based training program (CPT) to prevent and treat perinatal depression. Per recommendations from the BETA testing conducted in FY19, the content was updated to reflect the lifestyles of an urban population.

5. Loyola University Medical Center collaborated with non-birthing network hospitals to establish relationships and resources, including having an annual non-birthing hospital network meeting. Other activities included: all non-birthing hospitals participated in skill stations for OB hemorrhage, maternal hypertension and newborn stabilization; network hospital presented a quality project to the council each quarter; and all delivering network hospitals are participating in IDPH/ILPQC programs to improve care.

6. Rush University implemented a Lunch and Learn program to enhance our ability to provide education in several different ways. The APC utilized Network needs assessment to plan speakers. Education topics included STABLE, Basic Fetal Monitoring, AWHONN Intermediate Fetal Monitoring, AWHONN Advanced Fetal Monitoring, Ethical & Legal Considerations of FM, and Measles Isolation & Testing and Prevention of Perinatal Hepatitis B Transmission.

7. Javon Bea (formerly known as Rockford Memorial) successfully assisted the Perinatal Hospital in
their move to their new open campus by providing the Stork education for all of the emergency department (ED) staff to help prepare the ED at the new campus in becoming a Non-delivering Hospital ED, assisted in the planning for the simulation drills and education for the staff moving to the new campus, organized and assisted with the simulation check-off to be witness by another APC as required by IDPH, and assisted with the patient move process from the old campus location to the new campus location by performing the listed safety checks for each patient to be transported at one of three exit bays at the old campus location.

8. OSF St. Francis Medical Center implemented a comprehensive perinatal quality improvement project in the North Central Perinatal Network, focused on improving outcomes in Very Low Birth Weight Newborns, delivered outside the Level III Perinatal Center. The North Central Perinatal Network consists of one Level III Center and 14 regional maternity serve hospitals. The goal of the project is to increase survival without major morbidity from 50 to 55% in the Very Low Birth Weight Population born outside the Level III Center, by December 2020. This will involve standardizing care for all Very Low Birth Weight (VLBW) newborns delivered outside the Level III Center. The project team is composed of Maternal Fetal Medicine Specialists, Neonatologists, Neonatal Nurse Practitioners, NICU nursing staff, NICU Transport Team Members, and Respiratory Therapists.

9. South Central Illinois/St. John’s Children’s Hospital collaborated with Trauma Outreach Department to develop and present education specific to network area fire departments such as Trauma in the OB patient, Pre-hospital delivery, and Care and stabilization of the newborn. In addition, the APC collaborated with Department of Corrections providing education to pregnant inmates and the health care staff, including providing in-situ simulation events in the prison. Another notable activity of the APC was the provision of telemedicine services (MFM outpatient clinics, inpatient neonatology and newborn stabilization as needed) and establishing MFM telemedicine outpatient clinics throughout the South Central Perinatal Network.

10. St. Mary’s Hospital in Saint Louis (Cardinal Glennon network) successfully moved into the sustainability phase of the Illinois Severe Maternal Hypertension project. Each network birthing facility submitted a written plan on orientation of new staff and providers, and methods they will be utilizing to continue with the goals of early identification and treatment of severe maternal hypertension cases. The APC also held 21 M&M’s in which 210 cases were reviewed. Approximately, 33 cases involved severe maternal morbidity, 35 involved fetal deaths, 29 involved neonatal deaths and 2 involved maternal deaths. A total of 270 providers participated in the M&Ms and 432 other health professions (e.g., nurses, techs, social work, respiratory therapy) participated as well.

B. Collaborate with the Illinois Perinatal Quality Collaborative to implement quality improvement projects in birthing hospitals that will improve health outcomes.

3. Mothers and Newborns Affected by Opioids (2017-2019)

The support of Illinois’s IL Title V enables the Illinois Perinatal Quality Collaborative (ILPQC) to develop, implement, support, and sustain statewide quality improvement initiatives with nearly all of the birthing hospitals in the state in collaboration with the Illinois Department of Public Health (IDPH), State Quality Council, and the Regionalized Perinatal System as well as other state and national stakeholders. The statewide quality improvement initiatives support improved outcomes for mothers and newborns in Illinois related to our most pressing maternal and infant morbidity and mortality issues across hospitals. The Maternal Hypertension Project was formally completed in fall of 2017 and included the creation of a toolkit with resources for teams developed by ILPQC with national guidelines: http://ilpqc.org/?q=Hypertension. The efforts of the Maternal Hypertension Project were continued in
FY19 by partnering with the Regional Perinatal Network administrators and educators that were facilitating hospital team development of sustainability plans (template developed by ILPQC), as well as perinatal network discussions of hypertension sustainability at regional quality meetings.

During FY18, the Mothers and Newborns affected by Opioids (MNO) Initiative (MNO) was developed and initiated with both obstetric and neonatal arms. Activities included recruiting clinical experts to develop aims, measures, and key driver diagrams based on national guidelines including the Alliance for Innovation on Maternal Health (AIM) bundle and resources from other Perinatal Quality Collaboratives. Member volunteers were convened to develop the MNO Quality Improvement Toolkit building upon the AIM bundle and examples from other Perinatal Quality Collaboratives. A link to the toolkit developed by ILPQC with national guidelines for Teams is available here: http://ilpqc.org/?q=MNO-OB. ILPQC worked with IDPH in their efforts to develop patient education tools for hospitals, including the identification of focus group participants and developing the material content.

- Prescription Pain Medicines and Pregnant Women Neonatal Abstinence Syndrome - You are the Treatment Neonatal Abstinence Syndrome: What You Need to Know

ILPQC recruited 33 hospitals to participate in Wave 1 of the initiative with at least two from each perinatal network, where hospitals reviewed and provided feedback on the data collection form and process prior to launching the initiative statewide in Wave 2. Once launched, the initiative included collaborative learning opportunities for participating hospitals and rapid response data collection. ILPQC served on IDPH NAS Advisory Committee and supported the development of evidence-based recommendations using information already gathered for the MNO toolkit.

ILPQC facilitated several in-person collaborative meetings. The ILPQC 5th Annual Conference (December 19, 2017) had 101 hospital teams in attendance, including 400 physicians, nurses, and public health professionals. The annual obstetric face-to-face meeting (May 30, 2018) had 327 attendees and the annual neonatal face-to-face meeting (May 31, 2018) had 231 attendees, with over 100 individuals attending both face-to-face meetings.

In FY2019, ILPQC hosted 10 collaborative learning webinars (monthly October 2018 – September 2019) completed with over 60 participants per call focused on helping hospitals implement key strategies for success for MNO-OB, including: (1) screening all pregnant women for Substance Use Disorder (SUD) with a universal self-reported validated screening tool prenatally and on Labor & Delivery; (2) creation and implementation of MNO-OB folders to engage the OB provider and with tools to activate the clinical care protocol for patients with OUD; (3) materials to facilitate an OB provider education campaign; and (4) implementation of a missed opportunity review/debrief with the clinical team for every patient diagnosed with OUD. ILPQC facilitated hospital team round-robin on the webinars where all teams had a chance to share their progress and barriers to implementing the key strategies.

Rapid response data included access to the ILPQC data and reporting system with approximately 70 teams entering and monitoring monthly data in the ILPQC data system with over 1,500 mothers with Opioid-Use Disorder represented. There are 23 MNO-OB & Neonatal patient-focused reports created for teams to track progress on key initiative AIMS and measures. In addition, teams have access to two reports focused on monthly samples of deliveries tracking screening with a universal self-reported validated screening tool. Over 15,000 charts are included in the screening data set. Teams also have access to track monthly progress on implementing 6 key structure measures for MNO-OB and 4 key structure measures for MNO-Neo. All 10 perinatal network administrators have access to the ILPQC data system reports and are able to view each hospital in their network's progress on achieving the MNO initiatives. In addition, ILPQC staff provided cumulative comparative data for MNO-OB & Neo key initiative AIMs to hospital teams and perinatal network administrators.
QI support included 3 rounds of QI support to 36 hospitals in January 2019, about 30 in June 2019, and 29 in September 2019 to support hospitals working on implementing MNO Strategies including Screening, SBIRT, linking patients with OUD to MAT, implementing non-pharmacologic care, and coordinated discharge planning with the care team, family, and community pediatrician. ILPQC held 6 small group QI topic calls with 15-20 hospitals each during this period with QI Champions from hospitals sharing strategies for implementing Screening, SBIRT Protocol, Mapping Community Resources, the OUD/SBIRT Clinical Algorithm, OUD Clinical Care Checklist, and a monthly case review of all cases with OUD.

Key Resources developed to support efforts to engage OB Providers included:
- ILPQC SBIRT Pocket Card - resource for OB Provider to provide brief intervention, with SBIRT documentation and billing guidance
- OUD/SBIRT Clinical Algorithm - for pregnant/postpartum patients identified with Opioid Use Disorder
- Missed Opportunity Review / Debrief - tool to review monthly OUD cases to provide feedback to clinical teams
- ILPQC OUD Clinical Care Checklist - tool for OB providers to complete prenatally or by delivery for patients with OUD including Narcan counseling and prescription offer, Hepatitis C screening, peds/neonatal prenatal consult, etc.
- Narcan – Save a Life Poster; Key Counseling & Prescribing guidance for OB Providers
- Provider Poster (Mom & Baby) - key messaging for OB providers to link pregnant and postpartum women with OUD to MAT, provide Narcan Counseling, and link to recovery treatment programs
- Provider Poster (Provider & Patient) - key messaging every OB provider needs to know to save a mother’s life
- Education Poster #1 - Importance of screening all pregnant patients for OUD with a validated screening tool
- Education Poster #2 - Key strategies for caring for pregnant/postpartum patients with OUD
- Words Matter eModule from ILPQC 2018 Annual Conference

C. Convene partners to support statewide efforts to improve breastfeeding outcomes and reduce disparities.

The OWHFS is participating on a collaborative project known as the Illinois State Physical Activity and Nutrition Program (ISPA) which began in early 2019. This project aims to build on the significant accomplishments made already in physical activity and nutrition policy, systems, and environmental change. The purpose of this collaborative program is to reduce chronic disease and increase the health and well-being of Illinoisans by reducing disparities. This work focuses on equitable and just opportunities for Illinoisans to practice healthy eating habits and be physically active. Specific to OWHFS is the work that aims to increase the number of places (e.g., pediatric/family practices, WIC sites) that implement supportive breastfeeding interventions. The future of this work includes convening a statewide learning collaborative as well as training and support for local health departments, such as scholarships for WIC staff to become certified lactation consultants.

D. Support hospital Baby-Friendly designation by assessing barriers to progress and provide resources to assist hospitals in overcoming these barriers.

This strategy was completed in FY17 – no activities to report for FY20.

Though no new activities are planned for this strategy, Illinois will continue to monitor the number of
Baby-Friendly facilities and the proportion of births occurring in these facilities.

**E. Partner with the Illinois Department of Corrections and two state women's correctional centers to support ongoing health promotion activities for incarcerated women (including health education programs and lactation support) and prison staff training (same as strategy #1-B).**

*See Women's/Maternal Health Domain strategy 1-B narrative for details.*

**F. Provide support to pregnant women at risk for poor birth outcomes through an array of case management and home visiting programs through the Illinois Department of Human Services (DHS); Ensure DHS programs align with Title V priorities.**

The three main DHS projects being supported by Title V in this grant period (2015-2020) are: Better Birth Outcomes, Fetal Infant Mortality Review (FIMR), and Perinatal Depression Hotline.

**Better Birth Outcomes.** DHS contracts with local public health departments, community-based agencies, and Federally Qualified Health Centers to provide intensive prenatal case management services, known as the Better Birth Outcomes (BBO) program, to high-risk pregnant women in defined geographic areas of the state of Illinois with higher-than-average Medicaid costs associated with poor birth outcomes and higher than average numbers of women delivering premature infants.

During FY19, 85% of women who participated in the BBO Program began prenatal care in their first trimester and 94% of the women were active in the Medicaid program as well. Approximately, 68% of the BBO participants received adequate prenatal care per the Kotelchuck Index and 66% received counseling on reproductive life planning. It is estimated that 60% of the participants in BBO received contacts monthly during their pregnancies and 44% received a home visit in each trimester. Thirty-eight percent (38%) of women in BBO initiated breastfeeding. Staff reassessed birth data to ensure the program is continuing to be offered in the areas of highest need in Illinois.

**FIMR.** FIMR continues to examine and identify the significant health, social, economic, cultural, safety, and education systems factors (non-medical) that are associated with fetal and infant mortality through review of individual cases. FIMR identifies fetal deaths (infants born dead after the 20th week of gestation) and neonatal deaths (any live born infant regardless of gestational age and weight) who die within the first 28 days of life. Through the interviews with families who recently experienced a fetal loss, several challenges were identified, including inconsistent medical advice regarding interconceptual care and community changes impacting health (increase in community violence, gentrification in some communities, decreased rates of employment opportunities, and closing of local schools). The University of Chicago is responsible for administering the FIMR program and reviews deaths occurring within the city of Chicago. During FY2019, 46 cases were reviewed.

**Postpartum Depression Hotline.** Postpartum women in Chicago who experience signs & symptoms of postpartum depression can access Healthcare Alternative Systems to utilize pertinent services to improve and support positive mental health. Postpartum depression is an important public health issue and ongoing priority in Illinois. Almost one in five Illinois-resident women who deliver a live birth in the state will experience postpartum depression. Roughly two-thirds of those women will be diagnosed, and only 22% will receive some form of treatment. During FY19, 241 women were referred through different health facilities and treated for a duration of six to nine months. Some services that were utilized include Cognitive Behavior therapy (CBT), Psychodynamic therapy, and Rationale Emotive Behavior therapy (REBT).

**G. Distribute information on topics related to health in pregnancy to women through service**
providers and social media. Utilize materials from IL CHIPRA and leverage existing public awareness campaigns, such as Text4Baby and Connect4Tots.

The bulk of these activities are resulting from the state's Pre- and Inter-conception COILIN workgroup. The goal of this workgroup is to promote optimal women’s health before, after, and in between pregnancies as well as during postpartum visits and adolescent well visits. Beginning in FY18, the main facilitation of this workgroup was transferred to EverThrive Illinois through a grant agreement partially funded by Title V. In FY19, the created a logic model, refined an aim statement, outlined a plan for a gap analysis and gathered input on substantive updates for the Perinatal Education Toolkit. Through their Title V Mini-Grant, the Chicago Department of Public Health (CDPH) continued the Know and Go campaign to encourage early entry into prenatal care. The campaign includes a location finder for those seeking prenatal care or any other perinatal resources and was shared over social media. CDPH continues to update and support [www.HealthyChicagoBabies.org](http://www.HealthyChicagoBabies.org) and the resource page. The website is tailored to both providers and Chicago residents.

H. Provide home visiting services to families with newborns identified in the Adverse Pregnancy Outcome Reporting System (APORS) through the DHS High-Risk Infant Follow-Up Program.

Surveillance of adverse pregnancy outcomes began in Illinois in 1986 with the establishment of the Adverse Pregnancy Outcome Reporting System (APORS) -- the Illinois birth defect registry -- housed in IDPH's Division of Epidemiologic Studies. APORS has a two-fold purpose: 1) collection of adverse pregnancy outcomes for surveillance, policy development, and research; and 2) referral of high-risk newborns for community-based follow-up services. Hospitals are required to report babies meeting APORS case conditions within one week of their discharge from the hospital. Since 2002, APORS staff has been reviewing medical records to verify and further identify selected birth defects. To this end, hospitals make electronic medical records available through remote computer access or by providing the charts on paper or electronic media. Charts must be requested for most hospitals; most are available within two weeks, while a few can take up to two months. The chart of every baby reported with one of the selected birth defects, or with certain risk factors for one of the selected birth defects, is reviewed and every birth defect described in the chart is selected. The APORS program routinely uses birth and death certificates to identify APORS cases that may have been missed by hospital reporters. In addition, all cases are linked to birth certificates and, where applicable, death certificates.

The High-Risk Infant Follow-up Program is a case management program administered by the Illinois Department of Human Services. Based on eligibility established by APORS, public health nurses in local health departments provide follow-up home visiting services. There is a direct connection between high-risk follow-up and numerous programs such as WIC, Primary Care, Early Intervention, Perinatal Follow-up, and others depending on the needs of the family. Infants are followed until 24 months of age unless a complete assessment and the professional judgment of the nurse case manager indicate that services are no longer needed. In FY2019, 323 High-Risk Infant Follow-Up participants were active in a given quarter.

I. Support the Illinois Home Visiting Task Force in the design and implementation of Illinois Family Connects to offer universal home visiting to determine family support needs and refer them to appropriate services.

During FY19, the IL Title V supports home visiting in two ways. Firstly, the Title V Director served on the Illinois Home Visiting Task Force, which was coordinated by the Ounce of Prevention Fund and was a standing committee of Illinois’ Early Learning Council. This task force consisted of approximately 200 members representing state agencies and private sector health, early childhood, and child welfare organizations, as well as providers, researchers, and advocates. The task force worked with the Governor’s Office of Early Childhood Development to continue to advance the quality, quantity, and
coordination of home visiting services across the funding streams and relevant departments and served as the strategic advisory body for the MIECHV grant.

Secondly, IL Title V continued to support a universal home visiting program. The Universal Newborn Support System Pilot was coordinated by the Ounce of Prevention Fund and was championed by former Illinois first lady Diana Rauner, who co-chaired the Illinois Home Visiting Task Force since 2009. The pilot included two working pilot sites in Illinois where every woman receives a home visit to assess maternal and child health and well-being after a baby is born. One was in Stephenson County (Memorial Hospital in Freeport, Illinois) and one was in Peoria.

This pilot morphed into the Illinois Family Connects program. The CDPH intends to implement a Family Connects Chicago. Planning activities included designing the community alignment function of Family Connects, building relationships with partner hospitals, training our nursing team on the model, and engaging an evaluation team to measure impact and conduct an implementation study to inform plans to bring the pilot to scale. Family Connects is a community-based, universal program for parents of newborns, regardless of income or socioeconomic status. The support provided by the program includes wellness checks for the baby and family and help to identify and connect with supportive resources from which any new family may benefit.

CDPH intends to implement a Family Connects program in the City of Chicago beginning in 2019. CDPH continued to work on the development of a blueprint for a plan to establish a coordinated, citywide, centralized intake system for all pregnant women and children zero to two years of age. This effort will work to connect families to appropriate services (including early childhood) and reduce duplication of services.

**J. Through the CoIIN Safe Sleep workgroup, create a safe sleep toolkit that provides educational information to hospitals, home visiting agencies, childcares, and other organizations on developing evidence-based safe sleep policies.**

The goal of this team is to improve safe sleep practices statewide. The Illinois Safe Sleep CoIIN Team has worked together to develop and distribute a statewide hospital survey to all birthing hospitals and pediatric hospitals that also care for infants under the age of one year in order to assess the implementation of a safe sleep policy. Work is underway reviewing safe sleep education for hospital emergency department staff in Illinois. In training hospital staff, the team works to put the burden of teaching infant safe sleep recommendations on the staff. The recommendations are based on those suggested by the AAP. Findings thus far are that while the teaching styles are different, the message stays consistent. The team is also currently working on the development of an educational safe sleep tool kit as well as programs for home visitors to teach safe sleep. The main facilitation of this workgroup was transferred to EverThrive Illinois through a grant agreement partially funded by Title V.

**K. Participate in IDPH Zika Action Team to develop state readiness plan emphasizing needs of MCH populations. Ensure public messaging includes information related to pregnancy prevention, distribute educational materials to partners, and support APORS in enhancing microcephaly surveillance.**

*This strategy was completed in FY17 – there are no activities to report for FY18.*

**L. Collaborate with DPH Lead Prevention Program and other partners on the CoIIN Maternal and Child Environmental Health workgroup to update screening questionnaire, guidelines, and resources on lead exposure for pregnant women.**

Illinois is participating in a cross-disciplinary Maternal and Child Environmental Health Collaborative,
Improvement, and Innovation Network (CoIIN) to reduce infant mortality and morbidity by addressing lead exposure during pregnancy. The goal is for all pregnant women in Illinois to be assessed for lead exposure risk during pregnancy. IL Title V staff are working with IDPH’s Environmental Health and Lead Prevention Programs to create and update educational materials for pregnant women, revise the prenatal risk assessment and screening guidelines, and determine the prevalence of blood lead testing among pregnant women in Illinois. Ultimately, the CoIIN team will provide training to maternal care providers to raise awareness of these materials and increase completeness of blood lead testing to the state. During FY19, IL Title V staff participated in routine meetings for the CoIIN, provided clinical expertise in reviewing materials, assisted in the creation of a logic model for activities focused on increasing lead risk assessments/blood lead tests among pregnant women, and the development of a survey to OB/GYNs around knowledge and lead screening practices within two high-risk areas of the state for childhood lead exposure.

M. Ensure population-based metabolic and hearing screening for Illinois newborns.

Universal newborn blood spot screening is offered through the IDPH Newborn Screening Section (NBS). All Core RUSP conditions are included in the Illinois newborn screening panel. There were 138,025 live births in Illinois in 2019. When including duplicate samples for babies requiring repeat screens and follow-up, a total of 165,046 newborn blood spot screening specimens were processed for 2019 births. Of the 165,046 screenings, 6,022 (3.65%) had a presumptive positive screening for at least one of the Core RUSP conditions and those babies were referred for further testing. Of those referred for testing, 438 (7.275%) were confirmed as having at least one Core RUSP condition and those babies were referred for treatment. Newborns diagnosed through newborn screening are followed annually through fifteen years of age with staff of the Newborn Screening Program contacting the pediatric subspecialist to verify compliance with treatment and to monitor growth and developmental milestones. If needed, cases are referred to a local public health nurse to provide family assistance. Currently, no screening data or reports of diagnosed cases of newborns with a critical congenital heart defect are reported to the Newborn Screening Program, however families of all newborns with such a diagnosis are reported to the Adverse Pregnancy Outcomes Reporting System (state birth defects registry), which provides periodic follow-up by a public health nurse through two years of age.

The IDPH Early Hearing Detection and Intervention (EHDI) Program provides tracking, monitoring and referrals for Universal Newborn Hearing Screening for infants born in Illinois. During FFY 2019, 136,614 out of 138,025 infants reported to the EHDI program received inpatient hearing screening prior to hospital discharge. Of those screened, 4,377 (3.2%) referred for further testing, (0.4%) died prior to testing and 1572 (1.1%) were not screened prior to discharge. Of those referred for further testing after inpatient or outpatient screening, 316 (incidence of 2.289/1000) were documented as having a permanent congenital atypical hearing status. All newborns identified with atypical hearing are referred to Early Intervention services and to the state Children with Special Health Care Needs Program (through UIC-DSCC) which offers ongoing follow-up services. (data as of 7.27.2020 per the EHDI-information system at IDPH).

CDPH worked in partnership with the UIC-DSCC to provide nursing staff training on using OAE portable hearing screening machines. CDPH nurses will now do home visits and follow-up on children who failed their hearing screening upon discharge from the hospital at birth who did not return for follow-up.
Child Health - Annual Report

Illinois’ priority for the Child Health Domain is:

- Support expanded access to and integration of early childhood services and systems (Priority #3)

The IL Title V utilized the following strategies, as listed in the State Action Plan to address Priority #3 - Support expanded access to and integration of early childhood services and systems:

A. Work with the Governor’s Office of Early Childhood Development and the Illinois Early Learning Council to develop an environmental scan of developmental screening, including social and emotional screens, that contains options for data collection, places of screening, and validated screening tools.

_This strategy was completed in FY17 – there are no activities to report for FY19._

B. Collaborate with the UIC Leadership and Education on Neurodevelopment and other Disabilities (LEND) program to train early childhood providers to conduct autism screening while conducting developmental and social/emotional screens.

_This strategy was completed in FY17 – there are no activities to report for FY19._

C. Participate on the Governor’s Children’s Cabinet and Illinois Early Learning Council to facilitate coordination between early childhood systems and assure that health is recognized as an integral component of improving children’s educational outcomes.

During FY19, the Title V Director served all on three entities, ensuring that public health had a voice at the table to influence priority setting and the leveraging of Title V resources as needed. The Title V Director also participated in the BUILD Initiative for several years, which is a subset of the Executive Committee of the Illinois Early Learning Council. The Title V Director was also involved in the planning for the state’s first Risk and Reach Report which provides county-level data on the well-being of children in the areas of Family Stability, Health, and Early Care & Education to inform policies and programs. The state’s MCH Epidemiology Assignee also provided data for several of the indicators.

The report was published in April 2019 and is available on [Erickson Institute’s website](https://www.erickson.edu).  

D. Collaborate with home visiting programs, including the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program and early childhood providers to encourage alignment of activities.

IL Title V collaborates with various early childhood systems and programs in a variety of ways. During 2019, the Title V Director participated routinely in statewide committees such as the Early Learning Council and the Home Visiting Task Force where she served as chair. IL Title V also continues to connect MIECHV and home visiting programs to our other partners for collaboration and support.

While the CDPH Nursing and Support Services under the mini-Title V grant are largely focused on maternal and infant health, CDPH’s home visiting nurses provide support, guidance and referrals for families who need assistance and services for older children. Examples include referrals for daycare and pre-k programs, pediatricians, early intervention and benefit programs like WIC and SNAP.

E. Convene partners to develop administrative rules and coordinate implementation of a new state
law requiring social/emotional screening during school physicals.

During FY18, OWFHS leadership, the Title V Director, and the School Health Program led an ad hoc workgroup to develop a draft rule and solicit feedback from other offices within IDPH as well as outside partners. In Spring 2019, the rule language was submitted through the formal processes for review and eventually adoption.

Through their mini-Title V Block Grant, CDPH continued to work with Chicago Public Schools’ Office of Student Health and Wellness to continuously improve the student health forms booklet that provides information and color-coded consent forms for parents. For the 2018-2019 School Year, CDPH in collaboration with the Chicago Public Schools (CPS) continued to have a strong focus on Medicaid enrollment which included support for a CPS travelling enrollment team conducts outreach to schools.

The IL Title V utilized the following strategies to support ongoing efforts to improve asthma management in the school and community setting:

A. Improve asthma identification and support services, including education of families, referral of children with asthma to appropriate health care and social services, and care coordination through community-based partnerships.

This strategy was completed in FY18 – there are no activities to report for FY19. However, it is important to note that during FY18, the program reached over 5,800 people with asthma education and/or care coordination.

B. Provide training, support, and technical assistance to school nurses in Illinois.

During the Fall of 2018 (FY19), the IDPH School Health Program hosted School Health Days at five locations statewide. The trainings included transition care, pediatric trauma, palliative care and DNR, ISBE requirements, and legal issues in school nursing and adolescent health. Nearly 900 school nurses across the state attended the sessions.

The School Health Program partnered with the Illinois State Board of Education (ISBE) to provide a Back-to-School webinar in August 2019 to discuss requirements of the Child Health Exam, Communicable Disease and Immunization updates.

IL Title V staff participated in the School Health Services National Quality Initiative Collaborative Improvement and Innovation Network (NQI CoIIN) for School-Based Health Centers. The NQI CoIIN officially launch in August 2019 with the National School-Based Health Alliance convening in October to do a site visit and training for the CoIIN Team.

The IL Title V utilized the following strategies to increase access to preventive oral health services:

A. Financially support IDPH Division of Oral Health to provide dental sealants to children, particularly those with Medicaid or without dental insurance.

IDPH Division of Oral Health (DOH) assists Illinois school children who are most at risk for dental caries by granting funds, providing technical assistance, and providing training to public health departments and to other public not-for-profit service providers to develop and implement community-based oral health programs. In FY19, with the support of IL Title V, DOH funded 30 agencies to provide sealants to selected permanent molars for eligible children through the Illinois Dental Sealant Program. This program is designed to assist school personnel and families by assuring access to oral health
education, fluoride varnish, Illinois All Kids (Medicaid) enrollment, and referral to a dental home. The program also helps families comply with Illinois’ mandatory school dental examinations for children in kindergarten, second, and sixth grades. During FY19, approximately 186,000 sealants were placed on nearly 121,000 children.

Grantees were required to have a specific process for referral and case management to the oral health care delivery system for children found to need treatment services. Two grantees used mobile restorative equipment and schedules visits to establish a continuation of care and case management as a mobile dental home. Nine grantees referred the children back to the school-based provider’s office to provide necessary follow-up care and establish a dental home. The remaining grantees provided follow-up care through either a dental provider willing to accept the child into their practice or a health department clinic or Federally Qualified Health Center (FQHC). It is acknowledged, however, that accessing follow-up dental care to complete treatment plan for uninsured children continues to be a barrier.

B. Collaborate with IDPH Division of Oral Health to convene stakeholders and develop a statewide report and resource manual on oral health during pregnancy and early childhood.

See Women’s/Maternal Health Domain strategy 1-F narrative for details.

C. Participate in Implementation of Quality Indicators to Improve the Oral Health of the Maternal and Child Health Population Pilot Project with IDPH Division of Oral Health to pilot a series of measures for children and pregnant women to inform the creation of a national set of indicators.

In FY2019, in addition to continuing the Illinois Dental Sealant Program, DOH embarked on a new initiative focused on enhancing oral health surveillance. DOH continued to work with HFS to promote and understand the reach of preventive and periodontal care received by women during pregnancy. Once the Oral Health During Pregnancy and Early Childhood in Illinois resource manual is published IL Title V will support the dissemination and uptake of these resources.

The Title V Data Manager/Epidemiologist provided support in the Implementation of Quality Indicators to Improve the Oral Health of the Maternal and Child Health Population Pilot Project through data analysis and reporting as well as technical advising. In addition to Title V funds, this pilot received support from the Center for Oral Health Systems Integration and Improvement (COHSII) consortium as well.
Adolescent Health - Annual Report

Illinois’ priorities for the Adolescent Health Domain are:

- Empower adolescents to adopt healthy behaviors (Priority #5)
- Assure appropriate transition planning and services for adolescents and young adults including youth with special health care needs. (Priority #6)

The IL Title V utilized the following strategies, as listed in the State Action Plan, to address the Adolescent Health Domain priorities:

A. Certify and financially support school-based and school-linked health centers to expand access to primary health care, mental health, and oral health services for Illinois children and adolescents.

The School Health Program monitors the 66 school health centers operating in Illinois for compliance with TITLE 77 CH V: DEPARTMENT OF HUMAN SERVICES SUBCHAPTER J: SCHOOL-BASED/LINKED HEALTH CENTERS PART 2200. 42. IDPH combined Title V funds with general revenue and tobacco settlement funds to support almost 60% of these school health centers.

The purpose the program is to improve the overall physical and emotional health of school-aged children and youth by promoting healthy lifestyles and providing accessible preventive health care. School health centers assure students are healthy and ready to learn through services that focus on early detection and treatment of chronic and acute health problems; assist in the identification of risk-taking behaviors; and promote appropriate anticipatory guidance, treatment, and referral. Program staff conduct an annual site visit for each certified school health center (n=66) to determine compliance with Illinois statutory and current medical practice standards. During FY19, a total of 142,141 visits were provided to approximately 50,087 clients.

All school health centers are required to have an advisory board composed of health and education personnel, community agencies, parents, and students which is convened at least once per school year to determine priorities, develop and implement interventions designed to address those needs, and ensure the client and community voice is heard. Those centers receiving grant funding work towards achieving the following performance standards: risk assessment completed using Bright Futures tools; screening for clinical depression; adequate assessment for students with a BMI percentile >85th percentile (documentation of BMI percentile, counseling for nutrition, counseling for physical activity, and referral for nutrition counseling if needed), testing for sexually transmitted infections, full immunization status, HPV vaccinations, and transition planning from child- to adult-oriented care.

School-based health centers submit quarterly and annual data on its services. During FY19, the School Health Program continued to make improvements in its data collection and analysis processes to ensure effective and efficient analysis of the School Health Program. IDPH has continued to fund a graduate student intern to assist with updating and maintaining the database and creating state-level reports.

B. Provide training, support, and technical assistance to school nurses in Illinois.

During the Fall of 2018 (FY19), the IDPH School Health Program hosted School Health Days at five locations statewide. The trainings included transition care, pediatric trauma, palliative care and DNR, ISBE requirements, and legal issues in school nursing and adolescent health. Nearly 900 school nurses across the state attended the sessions.
The School Health Program partnered with the Illinois State Board of Education (ISBE) to provide a Back-to-School webinar in August 2019 to discuss requirements of the Child Health Exam, Communicable Disease and Immunization updates.

IL Title V staff participated in the School Health Services National Quality Initiative Collaborative Improvement and Innovation Network (NQI CoIIN) for School-Based Health Centers. The NQI CoIIN officially launched in August 2019 with the National School-Based Health Alliance convening in October to do a site visit and training for the CoIIN Team.

C. Facilitate collaboration of School-based health centers (SBHCs) and the state Family Planning (Title X) program to directly provide family planning services in SBHCs.

Progress in this area has been slow. The Title V Data Manager calculated teen birth rates by county to identify potential areas in need of family planning services by teens. The Title V Data Manager also worked with School Health Program staff to analyze results from a school health center survey to identify centers that are currently providing family planning services on-site versus referral.

D. Work with the Illinois Chapter of the American Academy of Pediatrics to encourage providers to adopt “adolescent-friendly” principles in their practice.

The Adolescent Health Initiative was first funded in FY19 and provided grants to 12 entities, including 11 local organizations to support the local implementation of strategies and support in order to increase the percentage of adolescents who received preventive and primary health care. IDPH also funds the Illinois Chapter of the American Academy of Pediatrics to continue to develop and provide training and support for health care providers to expand adolescent-friendly health care services. Methods used by local organizations include providing more youth-friendly waiting areas, social media campaigns, conducting youth focus groups, and various modes of outreach and education.

As a grantee of the Adolescent Health Initiative, the Illinois Chapter of the American Academy of Pediatrics developed provider and adolescent/teen surveys and conducted outreach to each individual grantee surveying their organizational needs, and developed and offered five webinar trainings:

- Transitioning Youth to Adult Health Care for Pediatric Providers (January 25, 2019)
- The Teen Brain (February 22, 2019)
- Counseling Teens on Sexual Health and Risky Behaviors (March 22, 2019)
- Bright Futures Guidelines, Implementation for Adolescents (11-21 years) (April 26, 2019)
- Use of Social Media for Patient Outreach (May 24, 2019)

In addition, ICAAP developed and shared educational tools via social media, to their membership, and to the grantees of the Adolescent Health Initiative to help in increasing well-visits.

E. Implement an Adolescent Health Initiative to support communities’ efforts to increase adolescents’ access to preventive and primary health care, and to increase the number of adolescent-friendly clinics.

To assist in addressing NPM #10 and both strategies D and E above, the IL Title V launched the Adolescent Health Initiative to empower adolescents to adopt healthy behaviors and improve the overall health of adolescents by increasing the rate of adolescent well-care visits.

The Adolescent Health Initiative was first funded in FY19 and provided grants to 12 entities, including 11 local organizations to support the local implementation of strategies and support in order to increase the
percentage of adolescents who received preventive and primary health care. IDPH also funds the Illinois Chapter of the American Academy of Pediatrics to continue to develop and provide training and support for health care providers to expand adolescent-friendly health care services. Methods used by local organizations include providing more youth-friendly waiting areas, social media campaigns, conducting youth focus groups, and various modes of outreach and education.

A total of 9,973 adolescents (ages 11-21) were reached/educated on the importance of well care visits, as well as their medical rights in Illinois.

Key accomplishments of the grantees, except ICAAP which are mentioned above, are as follows:

- Adams County Health Department: Developed an active mobile unit called Wellness Express - conducted back to school and sport physical for communities impacted.

- Adults Active in Youth Development, Inc.: Developed a PSA promoting wellness was developed, distributed and viewed at a local school and at a local medical facility by approximately 600 parents and children.

- Aunt Martha’s Health and Wellness: Implemented a depression screening questionnaire (Patient Health Questionnaire) and facilitated warm handoff to Behavioral health staff as necessary.

- Champaign-Urbana Public Health District (CUPHD): Held a Health Education Leadership & Learning (HEALS) conference in which 70 individuals attended and learned about the Adolescent Health Initiative and CUPHD’s adolescent health activities. Also partnered with advertising company to run digital ads targeting parents and adolescents and communicating the importance of well-care visits. The advertisements had over 210,000 impressions.

- Cook County Health & Hospital System (CCHHS): Provided CCHHS vans to provide adolescents transportation to the Health Clinic. Also created an adolescent –oriented short video on YouTube describing the importance of preventive care of adolescents (https://youtu.be/tkROynjexQw).

- DuPage County Health Department: Worked with two private practice pediatricians’ offices to make their practices more adolescent friendly and make easy referrals to Title X clinics near their offices. Each provider completed the Adolescent Centered Environment- Assessment Process (ACE-AP) center assessment tool and developed strategies and action steps to make their practices more welcoming and accessible for young people.

- Hult Center for Healthy Living: Convened Peer Leaders to implement a school-wide campaign for Teen Health Week to promote awareness of their In-School Health Clinics. Also established an Adolescent Health Team that includes five areas of adolescent health. As students are recruited for wraparound services, the team will meet to determine the best approach of care for each client.

- Kankakee County Health Department: Provided adolescent health presentations throughout grant year to local organizations providing services to adolescent population. Partnered with 20 local healthcare provider offices to enhance the status of youth-centered care. Targeted social media messaging to promote: cervical cancer prevention, human trafficking awareness/ prevention, Opioid awareness and Narcan training, nutrition, vaccination promotion, driving safety, STD prevention, teen dating violence awareness/prevention, alcohol awareness, mental health, teen pregnancy, family health and fitness, sun safety, importance of wellness visits for adolescents, and empowerment for youth girls.
Loyola University of Chicago: Leveraging its connection to a School Based Health Center increased the number of medical nutrition visits for individual PEHS students by expanding hours of registered dietician. Also increased the amount of behavioral health education and services available to Middle school students by having Spanish speaking SBHC social worker on site in District 89 Middle schools two days per week.

Perry County Health Department: Developed youth friendly material for sexual health and increasing well-care visits. The material included information on services offered at The Perry County Health Department, sexual health pamphlets, STD pamphlets, HPV vaccine information, a handout promoting a healthy future – A guide for yearly well-care visits for adolescents ages 11-21, and a handout for students to encourage then to take charge of their health.

Will County Health Department: Created 41 unique social media messages that were shared on both the Will County Health Department Facebook and Twitter pages. Incorporated into Electronic Health Records Manager well-care text messages followed by well-care emails to be sent to the 2,308 CHC parents of patients aged 11-17 and 2,038 CHC patients aged 18-21. Will County also developed educational material to distribute to students and families regarding insurance/Medicaid enrollment assistance, comprehensive list of all adolescent health services at the Will County Community Health Center, sexual health and minor consent laws, behavioral health programs, and well care visit reminders.

Additionally, through their Title V funded MCH Mini-Grant, the Chicago Department of Public Health (CDPH) implements their CHAT Program (Chicago Healthy Adolescents & Teens) which provides on-site sexual health education, optional and confidential testing for gonorrhea and chlamydia, private one-on-one counseling with a health educator, and linkage to health care services. CHAT now includes a comprehensive website which provides accessible content and education to adolescents in Chicago and beyond (www.chataboutit.org) as well as a brochure that describes and promotes the program.

CDPH continues the Condom Availability Program (CAP), which included the placement of condom dispensers with free condoms in Chicago Public Schools (CPS) high schools, school-based health centers, mobile health units, and City Colleges of Chicago. CDPH also continues to participate on the Contraceptive Justice Coalition convened by EverThrive Illinois.

In addition, CDPH continues to work with MIKVA Challenge to support the mental health of adolescents and empower peers to support their peers and for educators to offer more youth friendly approaches

F. Serve on statewide Adolescent Suicide ad hoc Committee to develop strategic plan to reduce suicide ideation and behavior among youth in Illinois.

IDPH collaborated with the IDPH’s Injury and Violence Prevention Program to convene the Adolescent Suicide Ad Hoc Committee to leverage expertise and to develop a strategic plan to: Increase awareness, knowledge, and competency in suicide prevention, assessment, and treatment for first responders, health care workers, social service workers, clergy, law enforcement, and school personnel; Promote utilization of suicide prevention services for victims of harassment and violence; Advocate for a comprehensive continuum of care for those at highest risk for suicide.

Increase the awareness of the burden of suicide and how individuals and communities can be part of prevention efforts; Improve suicide-related data collection; and Develop sustainable funding sources for implementing suicide prevention intervention and crisis response/aftercare programs in Illinois and for evaluation of the results in order to save more lives.
For FY20, IL Title V will provide funding to support a graduate intern position to facilitate the Adolescent Suicide Ad Hoc Committee’s activities.

**G. Partner with school-based health centers and other interested providers to educate and encourage pediatric providers to incorporate transition into routine adolescent well visits, and to use a standardized transition tool (e.g., Physician Resource Tools housed on ICAAP’s website, including the transition checklist [readiness assessment], the Portable Medical Summary, and the informational skill sheets, along with the Six Core Elements of Health Care Transition).**

During FY19, a transition care needs assessment developed. Based on the information generated from the assessment, it was determined that centers would establish criteria and processes for identifying and tracking transitioning youth and young adult SBHC clients 14 years of age and older. In addition, SBHC’s will conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth their needs and goals in self-care. IDPH continues to address the challenges in tracking and monitoring transition progress in the multiple electronic health records utilized by the school-based health centers.
Illinois’ priorities for the Children and Youth with Special Health Care Needs Domain are:

- Enhance the capacity of families to connect CYSHCN to the health and human services they require for optimal behavioral, developmental, health, and wellness outcomes. (Priority #4)
- Assure appropriate transition planning and services for adolescents and young adults including youth with special health care needs. (Priority #6)

Illinois has prioritized care coordination and transition services for children and youth with special health care needs (CYSHCN). Current data on the experience of Illinois’ CYSHCN from the 2016 and 2017 National Surveys of Children’s Health, as well as Illinois’ national and regional ranking and ranking among the 10 most populous states on the six core outcomes for systems serving CYSHCN were presented in the “Needs Assessment Update” section.

The UIC-DSCC utilized the following strategies and activities to address the Children and Youth with Special Health Care Needs Domain priorities:

DSCC provided care coordination services for 7,554 individuals located in all Illinois counties, and provided resource and referral information to another 11,685 children who were not interested or eligible for ongoing care coordination services.

**Care Coordination.** UIC-DSCC has care coordination programs serving children with special needs and works to address systemic issues impacting CYSHCN throughout the state. The mission of UIC-DSCC is to partner with Illinois families and communities to help children and youth with special healthcare needs connect to services and resources. UIC-DSCC’s work with CYSHCN across the state of IL helps UIC-DSCC to have a deeper level of awareness of issues impacting individuals and their families. It also helps to create relationships with various programs serving children which is beneficial when working to develop solutions to problems or addressing strategic initiatives.

UIC-DSCC has 3 programs of care coordination services. The Core Program is guided by Illinois Administrative Rule, which was updated October 2018, serves a broad population of CYSHCN, and is funded by Title V dollars. The revision of the Administrative Rule involved implementation of significant policy and procedure revisions. The policy revisions also included some changes to the financial assistance provided to participants of the Core Program. An individual cap of $7,500 was put into place. UIC-DSCC does continue to offer “gap-filling” financial assistance to program participants. Work to strengthening organization policy and procedure continued throughout the year.

A Core Program Enrollment & Resource Team began piloting in summer 2019 in Chicago. The goal of this team is to improve the ability of DSCC to provide assistance to CYSHCN and their families throughout the state with resource needs who are not enrolled in our care coordination programs. To better accommodate the growing Chicago Core team, plans began in late summer 2019 to open a new Chicago region.

The second key program is the Home Care Program which serves medically complex individuals who receive in-home, shift based nursing care as a Medicaid EPSDT benefit or who are enrolled in the Medically Fragile Technology Dependent Waiver. This program is administered and funded by the Illinois Department of Healthcare and Family Services (HFS). UIC-DSCC provides services necessary for the operation of this program and provides care coordination. Several changes were made to the Home Care Program in FY 2019 to accommodate for continued program growth. These changes included the development of a dedicated enrollment team, the implementation of a 6th regional team, and the development of a Staffing Support Team dedicated to helping address...
systematic issues pertaining to home nurse staffing.

As part of its role with the Home Care Program, UIC-DSCC provides quality oversight of home nursing agencies and medical equipment companies throughout the state serving MFTD waiver recipients. During FY2019, DSCC developed a more collaborative relationship with IDPH. This has improved the way that quality issues are addressed by the home nursing agencies.

In July 2019, UIC-DSCC began to develop and implement its third program of care coordination for CYSHCN, the Connect Care Program. This program provides care coordination for children who were previously served by DSCC’s Core Program, and who are now enrolled in one of 6 Medicaid Managed Care Organizations who DSCC will contract with to provide care coordination. The Connect Care Program will be funded by reimbursement from the Medicaid Managed Care Plans.

**Population-Based Approaches.** UIC-DSCC has been actively participating in the “Big Five States” workgroup on population-based approaches to serving CYSHCN and in the National Pediatric Home Health Care Panel and will continue to pursue population-based approaches to serving CYSHCN and their families through the Core and Home Care Programs.

UIC-DSCC’s outreach strategy includes presentations and exhibits at conferences sponsored by partner organizations. The Transition Conference targets youth with all types of special health care needs, as well as their families and the providers and agencies who serve them. UIC-DSCC’s Early Hearing Detection and Intervention grant supports a successful collaboration to reduce the number of infants with hearing loss who “drop out” of the service delivery system.

**Medical Home.** In FY2019, UIC-DSCC continued to train its Care Coordinators to help families develop the skills to recognize, advocate for, and successfully participate in patient-centered medical care. It also continued to promote the National Center for Medical Home Implementation through staff training and by listing Illinois-specific efforts on its public website and social media platforms. In addition, UIC-DSCC staff participated in a variety of state-wide councils or advisory committees pertaining to CYSHCN including Illinois Chapter of the American Academy of Pediatrics (ICAAP) Section Committee on Chronic Illness & Disability, Children’s Justice Task Force, advisory committee for Integrated Health Homes along with HFS, Integrated Care for Kids Partnership Council at Lurie Children’s Hospital, Emergency Medical Services for Children, The Collaborative for Children’s Healthy Policy, Transition Planning Councils, and IL Interagency Council on Early Intervention.

**Transition Staff Training and Assessment Tools.** Staff training on transition includes assessment of transition readiness, specification of transition goals in the care plan, follow-up with youth and families, and advocacy with providers. The transition assessment is tailored to address the concerns of specific age groups. UIC-DSCC will use a continuous quality improvement approach to strengthen assessment, planning, and plan implementation for CYSHCN participating in its Core and Home Care Programs. Further assessment, training, and dissemination of best practices will strengthen transition planning and plan implementation. Evidence of UIC-DSCC’s commitment to strengthening transition planning it began requiring a transition related goal be included in the person-centered care plan for all individuals enrolled in any of UIC-DSCC’s care coordination programs. This activity will be monitored through the record review process with results available in the UIC-DSCC Scorecard.

**Transition Conference.** The 14th Annual Statewide Transition conference was held in the Chicago area in October 2018. There were 712 participants, including 129 parents and youth, and 583 professionals (educators, nurses, vocational counselors, and social workers). UIC-DSCC provided financial support for 27 youth and their families, along with 23 staff, to attend the conference. For the first time in many years, Continuing Medical Education credits were offered for physicians and advanced
practice nurses who attended the workshops in the Health Care Transition track and eight physicians presented workshops or plenary sessions for this track. Overwhelming positive evaluations from various fields, including veteran teachers and state rehabilitation services staff, show that participants continue to gain new knowledge and skills from the conference. Families report that they learn a great deal and are better able to plan for a successful transition. Many attendees return year after year.

Presentations. The UIC-DSCC’s Transition Specialist presented at 3 different events in the state (Webinar for IL Lifespan Program of the Arc in February 2019; School Nurses at the Special Education District of Lake County (SEDOL) March 2019; and a breakout session presentation at the Statewide Transition Conference in October 2018 titled, Partner, Help, Connect: Supporting Youth with Special Healthcare Needs and their families.

Partner with School-Based Health Centers. The Specialists also collaborated with Got Transition Technical Assistance and the School Health Program Administrator along with IDPH and School Based Health Center staff in July 2019. Based off the feedback, the IL School Based Health Centers added “transition services” to the problem list, and implemented an assessment shared by Got Transition to monitor their transition activities.

Illinois’ LEND Program. UIC-DSCC collaborated with five LEND trainees on a leadership project to develop a curriculum on Self-Determination in the Transition to Adulthood. This curriculum was presented to professionals, families and individuals with disabilities at 2 locations in IL in March 2019.

Outreach and Collaboration. To provide information on transition for the public, UIC-DSCC staff participated in outreach activities and transition fairs. The UIC-DSCC Transition Resource Directory provides important transition resources including “Transition Milestones,” “Transition Skills, Tips, and Tools,” and the “Transition Toolkit” and posted information about transition activities and resources on the website and Facebook page.
UIC-DSCC staff continued to work with the Family Advisory Council, providers, and other stakeholders to identify and disseminate additional resource materials on health care transition.

Family Partnership. UIC-DSCC addressed state priority #9, the proportion of children who experienced family-centered care, by continuing to partner with CYSHCN and their families by using a person-centered approach to care plan development. Every family that participates in UIC-DSCC’s care coordination programs is approached as an active and equal partner in the development and implementation of a care plan.

FY2019 was referred to as the year of the Family Voice at UIC-DSCC. Family surveys were developed and implemented in August 2019. These surveys are set to be delivered at intervals during enrollment in UIC-DSCC care coordination programs.

Coordination/Collaboration with key stakeholders to address barriers (including financial assistance). In July 2019 the IL Medicaid Program notified UIC-DSCC that children with special health care needs would be moving into mandatory managed care. UIC-DSCC was asked to partner with the 6 Medicaid Managed Care Plans (MCOs) to continue serving individuals who were already enrolled in the UIC-DSCC Core Program. UIC-DSCC developed a new care coordination program, Connect Care, in order to continue serving this population. The development of relationships with MCOs has allowed UIC-DSCC to make additional relationships with additional systems serving CYSHCN.

Additionally, in FY2019, UIC-DSCC provided $2.8 million dollars in direct “gap-filling” financial assistance to enrolled program participants who met financial eligibility and presented a need. In October 2018 UIC-DSCC along with Ann & Robert Lurie Children’s Hospital hosted the Nitty Gritty Nursing Conference. The intended audience of this conference was nurses who care for medically
complex children in the home setting. The conference was developed in response to some issues pertaining to the quality of nursing care provided in the home by nurses serving medically complex children. One key area identified with this issue was that the skills needed to care for this population are above what is taught in nursing school. While the team of experts at Lurie developed the content for this conference, UIC-DSCC has obtained the intellectual rights to this material. Approximately 75 people attended the event in October. UIC-DSCC worked with OSF Saint Francis Medical Center Children’s Hospital of Illinois to create an event in the central part of the state with the using the same content developed by the Lurie team. The Nitty Gritty Nursing Conference was highlighted in a June 2019 Health Affairs article, “Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, & Future Directions,” as a successful example of targeted nurse education.

**Workforce Development.** Another notable development in FY2019 focused on workforce development. UIC-DSCC Education and Training Specialists began an overhaul of the training provided to all new UIC-DSCC staff at the time of hire. This project also includes a revision of the care coordination training process. UIC-DSCC is working to ensure care coordinators are provided a better foundation at the time of hire to support their work. UIC-DSCC has also made a commitment to ensuring care coordination staff receive 20 hours of continuing education every year throughout their employment.

In May 2019 UIC-DSCC provided the first training to 16 Quality Champions. Quality Champions are staff volunteers from across the state who received additional quality improvement training. The Quality Champions will help within their team reviewing scorecard and other quality metrics, facilitating quality improvement huddles with their teams, and then developing plans for improvement within the team. Quality Champions as well as other members of UIC-DSCC leadership were provided training by the Institute for Health Care Improvement on quality improvement.

UIC-DSCC implemented monthly, statewide multidisciplinary staffing meetings. All staff were invited to participate in these meetings. Care coordinators presented on various challenges they have encountered. Staff then share knowledge and experience to help find solutions.

Trainings for UIC-DSCC staff for FY2019 included the following topics: abuse and neglect, AllKids & Medicaid training, Disability Culture and Current Views, Division of Rehabilitative Services (DRS) Transition Services and Home Services Program, General Eligibility for the DSCC Core Program, Annual HIPAA compliance training, Introduction to Medical Home, Introduction to Motivational Interviewing, MEDI training, Medicare Basics, Motivational Interviewing (2 sessions and application exercise), Sensitivity Training, Ventilator Basics, University Ethics, University Title IX Misconduct Training.

In FY2019, UIC-DSCC selected a new care coordination software, ClientTrack by Eccovia. Throughout FY2019 select team members participated in system testing and development activities in preparation for a March 2020 implementation.
Cross-Cutting/Systems Building - Annual Report

Illinois’ Title V priorities for the Cross-Cutting/Life Course Domain are:

- Assure that equity is the foundation of all decision-making; eliminate disparities in MCH outcomes (Priority #7) Support expanded access to and integration of mental health and substance use services and systems for the MCH population (Priority #8)
- Partner with consumers, families, and communities in decision-making across MCH programs, systems, and policies (Priority #9)
- Strengthen capacity for data collection, linkage, analysis, and dissemination; Improve MCH data systems and infrastructure (Priority #10)

Health Equity (Priority #7)

Illinois faces many challenges to reducing racial/ethnic disparities in health outcomes due to underlying systemic racism. In almost every health indicator measured for Title V, there are persistent and wide racial disparities that adversely affect vulnerable populations. SOM #3 (the black-white disparity in infant mortality) was developed as a sentinel indicator that would highlight a key racial disparity over time. Unfortunately, despite reductions in infant mortality overall, the disparity between black and white infants has not substantially changed over the last nine years.

Specifically, within infant mortality, sudden unexpected infant deaths have the highest black-white disparity, with black infants being more than 4 times as likely to die from this cause of death as white infants. Many other key MCH indicators also demonstrate significant racial disparities, including the chlamydia rate among young women (SOM #1), mental health and substance use hospitalizations for women of reproductive age (SOM #5), pediatric asthma hospitalizations (SOM #4), and youth suicide attempts (SPM #4).

One of the only key Title V measures without substantial racial/ethnic disparities is the percent of very low birth weight infants who are delivered in Level III facilities (NPM #3). Black, white, and Hispanic very low birth weight infants all have similar rates of risk-appropriate care. This speaks highly of the Illinois regionalized perinatal system, which prioritizes and facilitates transports to appropriate-level facilities for pregnant women and neonates.

In addition to racial/ethnic disparities, there are also other populations that do not have equitable outcomes. Geographic area, education level, income level, disability status, sex, and many other factors are risk markers for adverse outcomes. For example, the pediatric asthma hospitalization rate (SOM #4) is highest in the Chicago area, where the rate is nearly three times as high as that for rural counties. This may reflect the environmental risk factors that are more prevalent in urban areas. In contrast, mental health and substance use hospitalizations (SOM #5) are highest in rural counties and lower in the Chicago area, perhaps reflecting a lack of outpatient or community-based services for women in rural areas. Whenever possible and feasible, Title V data reports examine the distribution of outcomes by various population demographics and consider how this information can contribute to equitable program and policy development.

In the FY17 Annual Report and FY19 Application, Illinois Title V created a new SPM (#7) to determine the percent of MCH staff members who completed at least one training or professional development activity related to health equity during the last year. This measure will be reported for the first time this year. No changes to the SPM are being made at this time. SOM #5 was created this year as a new version of the inactive SOM #2, to accommodate for changes in ICD diagnosis codes.

The IL Title V utilizes the following strategies to address the Cross-Cutting/Life Course Domain
priority #7: assure that equity is the foundation of all decision-making; eliminate disparities in MCH outcomes:

A. Support the development and implementation of the online Infant Mortality Health Equity Toolkit through CoIIN Social Determinants of Health workgroup.

This strategy was completed during FY17 – no activities during 2018.

Toolkit is maintained on the EverThrive website: http://everthrivel.org/resources/infant-mortality-toolkit

B. Launch training on the use of the Infant Mortality Health Equity Toolkit to provide information and resources to local health departments and other organizations to incorporate an equity framework into planning.

This strategy was completed during FY17 – no activities during 2019.

C. Promote existing training resources on life course, health equity, and social determinants of health to members of boards/groups working on MCH issues.

Title V staff members, including the Title V Director, served on a variety of state and local committees, workgroups, councils, and task forces. Whenever possible, these staff members bring their knowledge of the life course, health equity, and social determinants of health to conversations in these groups.

One example of this work is in the transformation of the Illinois Maternal Mortality Review Committee (MMRC). Several years ago, the MMRC was focused almost exclusively on the clinical issues that contributed to a maternal death, without considering how a woman’s social context influenced her health and health care. Over the past few years, Title V staff have helped the MMRC re-frame the reviews to include discussion of contributing social and community factors and potential recommendations to address these factors.

D. Expand OWHFS (IDPH) requirements for describing disparities in grants/proposals and require demonstration of how health equity guides decision-making and program planning.

To enhance health equity across programs funded by the IL Title V and OWHFS, IDPH continued to add healthy equity deliverables to grant agreements. This included expectations that services were provided in a manner that is equitable to communities that are underserved, disadvantaged, reflect diverse backgrounds, and assured cultural and linguistic appropriateness. IL Title V also required grantees to collect data and report on demographics of those served in order to ensure that programs were appropriately targeted. IL Title V remains committed to health equity and plans to continuously review and adjust the language included in grant agreements to ensure a health equity lens in the grants and proposals it supports. No specific changes were made in FY19.

E. Participate on IDPH Health Equity Council.

The objective of the HEC is to support a work culture within IDPH that promotes health equity and eliminates health disparities through increased coordination with leadership, programs, and strategic partnerships. The HEC has three goals:

• Conduct an internal, agency-wide self-assessment to gather comprehensive information about strengths and areas of improvement that support institutional capacity to effectively address
health inequities, interpret those findings, and take action;

- Support a culturally competent workforce and development of department-wide standards to enhance health equity and as it relates to the mission, vision, values, and priorities of IDPH;
- Promote state-wide efforts and support public health partners on research and evidence-based best practices related to reducing health disparities.

During FY19, Title V staff served on the IDPH Health Equity Council (HEC) and to support IDPH-wide activities related to health equity.

F. Ensure that data reports produced by Title V describe relevant disparities and discuss potential root causes, implications, and recommendations for moving towards equity.

Data communication products produced by the Title V epidemiology team routinely include information on the relevant disparities for that measure, which may include differences by race/ethnicity, age, socioeconomic status, geography, disability status, or other relevant demographic factors. The purpose of including such information is not merely to point out differences, but to highlight inequities that may inform the targeting of resources to communities most affected by adverse health outcomes. Examples of data communication products are available in the strategies listed for Priority #10 (MCH data capacity and infrastructure).

G. Collaborate with Committee on Institutional Cooperation (CIC) and Big 10 universities on Health Equity-focused funding proposals supporting policy analysis and data collaboration.

This strategy was completed during FY18 – no activities during 2019.

Mental Health and Substance Use (Priority #8)

Addressing mental health and substance use continues to be a priority of the IL Title V, and many measures are used to track various dimensions of mental health and substance use in various MCH populations.

The IL Title V utilizes the following strategies to address the Cross-Cutting/Life Course Domain priority #8: support expanded access to and integration of mental health and substance use services and systems for the MCH population:

A. Support training on trauma-informed care, motivational interviewing, and mental health first aid for public health and medical professionals through webinars and other educational opportunities.

This strategy was completed during FY16 – no activities to report for FY19.

B. Partner with the State Health Improvement Plan (SHIP) Behavioral Health Action Team to carry out statewide strategies.

This strategy was completed during FY17 – no activities to report for FY19.

C. Partner with the Illinois Children’s Mental Health Partnership to develop and implement a model for children’s mental health consultations for local health departments and other public and private providers in the public health and health care delivery system.

Infant and early childhood mental health consultation is a multi-level, proactive approach that partners multi-disciplinary infant early childhood mental health professionals with people who work with young
children and their families to support and enhance children’s optimal social emotional development, health, and well-being. This approach aims to build the capacity of public health programs to prevent, identify, and reduce the impact of mental health concerns among infants, young children, and their families. IL Title V partnered with the Illinois Children’s Mental Health Partnership (ICMHP) and (IDPH) to integrate a model for infant and early childhood mental health consultation (IECMHC) into public health settings.

In FY 2019, ICMHP recruited four public health department sites (Stephenson County, Winnebago County, Southern Seven, and East St. Louis) to participate in the pilot; hired two I/ECMH consultants to serve the sites; modified the Universal Model of Infant/Early Childhood Mental Health Consultation for public health settings; and finalized the evaluation plan. It was noted that the pilot programs would have a special focus on WIC and Family Case Management programs, however, consultants would be available to anyone at the public health department as well. It is anticipated the pilot programs will be implemented in FY20 and will help address multiple Title V priority areas by building capacity and ensuring connections are made between appropriate systems and resources.

D. Develop state outcome measure on mental health and substance use among women of reproductive age; analyze data to demonstrate burden and importance of issue; develop data reports to disseminate findings.

Starting in FY19, Title V began working with a doctoral-level epidemiology student intern from the UIC CoE-MCH to deepen the epidemiologic work on the mental health and substance use hospitalization indicator (SOM #5). She verified the ICD-10 codes and calculated the MHSU indicator among sub-groups of women of reproductive age. In addition, she began the process of linking maternal delivery hospitalization records to birth certificates so that future analyses can look at the presence of MH/SU conditions at delivery by various maternal/infant characteristics. This data linkage will also allow for analyses of MH/SU and adverse birth and maternal outcomes. Her internship will continue through 2021.

E. Coordinate and support the state Neonatal Abstinence Syndrome (NAS) Advisory Committee, including organizing the annual report due to the legislature and implementing new data collection, reporting, and surveillance activities.

In 2015, the Neonatal Abstinence Syndrome (NAS) Advisory Committee was created pursuant to Section 2310-677 of the Civil Administrative Code of Illinois (Department of Public Health Powers and Duties Law) (20 ILCS 2310). The NAS Advisory Committee was comprised of 10 members appointed by the Director of IDPH. Members represented different racial, ethnic, geographic, and disciplinary backgrounds.

The Committee was charged with advising and assisting IDPH to:

- Develop an appropriate standard clinical definition of NAS
- Develop a uniform process of identifying NAS
- Develop protocols for training hospital personnel in implementing an appropriate and uniform process for identifying and treating NAS
- Identify and develop options for reporting NAS data to IDPH using existing or new data reporting options
- Make recommendations to IDPH on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS

In addition to attending the meetings and supporting the NAS Advisory Committee, Title V staff served as a bridge between the Committee and the Illinois Perinatal Quality Collaborative (ILPQC). This
coordination was essential to ensure that the work of the two entities was complementary, rather than duplicative or contradictory, especially regarding ILPQC’s Mothers and Newborns Affected by Opioids initiative. ILPQC staff members routinely attended the NAS Advisory Committee and actively contributed to the collection and synthesis of NAS resources.

Prior to finalizing its final report, the Committee reviewed The Illinois Maternal Morbidity and Mortality Report released by IDPH in October 2018 and found much alignment in recommendations. The final report of the Committee was submitted in March 2019, and the Committee was sunset in June 2019. The final report of the NAS Advisory Committee is available at: 

F. Partner with the Illinois Department of Corrections and Logan Women’s Prison on health promotion activities for incarcerated women focused on substance use recovery and trauma health education.

*This is the same as strategy 1-B. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.*

G. Identify pregnancy-associated deaths and facilitate two state Maternal Mortality Review Committees (including one focused on violent deaths); generate statewide report that summarizes public health recommendations for preventing such deaths.

*This is the same as strategy 1-C. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.*

H. Conduct environmental scan of Illinois’ opioid treatment locations that will treat pregnant women on Medicaid; Develop a directory to help health care providers appropriately refer women to the nearest community-based resources.

*This strategy was completed during FY18 – no activities to report for FY19.*

The final comprehensive list of resources in Illinois formed the Opioid Use Treatment Resources for Pregnant Women Insured by Medicaid guide is available at:

I. Collaborate with state initiatives to address opioids and substance use to ensure a focus on women of reproductive age.

During FY19, IDPH OWHFS and IL Title V continued to collaborate with state initiatives that are focused on opioids and substance use, such as the Governor’s Office Task Force on Opioids, the DHS Division of Substance Use Prevention and Recovery Women’s Committee, and the cross-sector opioid data workgroup led by IDPH. In these efforts, staff members continued to advocate for programs and policies that consider the unique needs and challenges of women of reproductive age, especially those who are pregnant or parenting.

J. Convene cross-agency partners in the ASTHO Opioid Use Disorder, Maternal Outcomes, Neonatal Abstinence Syndrome Initiative (OMNI) Learning Collaborative

During FY19, Illinois accepted an invitation to participate as one of 12 states in the first wave of the ASTHO Opioid Use Disorder, Maternal Outcomes, Neonatal Abstinence Syndrome Initiative (OMNI) Learning Collaborative. The Illinois team is comprised of representatives from the IDPH, HFS
(Medicaid), DHS, DCFS (child welfare), and the ILPQC. The team developed the following vision for the team’s OMNI project: “Illinois will have a recovery-oriented system of care that enables women planning pregnancy, and pregnant and postpartum women to receive medication-assisted treatment (MAT) and needed support services to have healthy pregnancies and deliveries and be supported in the postpartum period for the development of healthy families.” The team identified several barriers to MAT for women with substance use disorder (SUD), including lack of providers, lack of provider awareness/training, lack of care coordination and fragmented system, lack of identification/screening, reimbursement issues, prenatal care providers lacking experience and process to link women to MAT providers, stigma, and the social determinants of health (transportation, housing, child care). The goals of the project were:

- Expand access to MAT for pregnant women with SUD by increasing the number of providers trained to screen/diagnose SUD, administer MAT, and counsel patients;
- Develop a cross-system communication plan for the health care, Medicaid, substance use prevention/treatment, and child welfare systems that reduces stigma around substance use disorder and creates standardized systems of support for pregnant women with SUD and their infants; and
- Develop cross-system training for providers delivering prenatal care, labor/delivery staff in hospitals, and the child welfare system to establish standardized protocols and practices which would assure optimal care to infants born with Neonatal Abstinence Syndrome (NAS).

K. Partner with UIC Center for Research on Women and Gender to implement a program at two clinic sites to expand the capacity of health care providers in the state of Illinois to screen, assess, refer, and treat pregnant and postpartum women for depression and related behavioral health disorders. *(same as strategy 1-J)*

*This strategy is the same as strategy 1-J. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.*

L. Serve on the statewide Adolescent Suicide ad hoc Committee to develop a strategic plan to reduce suicide ideation and behavior among youth in Illinois. *(same as strategy 5-G)*

*This strategy is the same as strategy 5-G. Information about this activity is available in the narrative for the Adolescent Health Domain.*

**Family and Consumer Partnership (Priority #9):**

In FY19, IL Title V created a new SPM to count the number of active members of the Title V MCH Family Council. Active participation on the Councils was defined as attending at least half of meetings during the year. This measure will be reported for the first time. No changes to the SPM are being made at this time.

The IL Title V utilizes the following strategies to address the Cross-Cutting/Life Course Domain priority #9: partner with consumers, families and communities in decision-making across MCH programs, systems, and policies:

A. Implement a Title V MCH Family Council in each of the seven Illinois Public Health regions.

The Title V MCH Family Council is a consumer-led feedback group which represents the consumer perspective and makes recommendations to Illinois Title V on ways to enhance the consumer/family experience as it relates to MCH programs, systems, and policies. Guided by IDPH OWHFS vision, mission, and priorities, and facilitated by EverThrive Illinois, the Title V MCH Family Council is dedicated
to ensuring that consumers and their families have a safe, quality, compassionate, and supportive programmatic experience.

More specifically, the Councils is responsible for: (1) Representing the consumer perspective and make recommendations for improvement; (2) Advising IDPH OWHFS on ways to enhance the consumer/family experience; (3) Educating the community on consumer issues; (4) Supporting Title V staff and leadership in their consumer-centered activities and initiatives; and (5) Participating in committees and workgroups in order to provide consumer representation.

During FY19, EverThrive Illinois convened the annual Illinois MCH Family Council Retreat in June 2019. The retreat focused on mental health because of the Council members’ concerns over the rising mental health issues observed in their communities. The material presented during the retreat was aimed to help members better understand the effect of mental health on individuals and families and the resources available in their respective regions. There was a professional development session on Mental Health First Aid specifically tailored for the council members. This session covered the following topics:

- Understanding depression, anxiety disorder
- Crisis first aid for suicidal behavior & depressive symptom
- What is non-suicidal self-injury
- Non-crisis first aid for depression and anxiety
- Crisis first aid panic attacks, traumatic events
- Understanding psychosis and first aid for psychosis

In addition to the retreat, there were 21 regional MCH Family Council meetings over the course of the year. During these meetings, council members shared their perspectives on critical consumer issues and needs across the MCH populations’ lifespan. Members were also afforded the opportunity to participate in a variety of provider and community-based workgroups and collaborations, including the WIC Consumer Collaborative (Champaign), Campaign to Save Our Mothers and Babies (CSOMB), and the Contraceptive Justice Project.

B. Maintain the UIC-DSCC Family Advisory Council.

*Information about this activity is available in the narrative for the CSHCN Domain.*

C. Leverage existing community and family coalitions to obtain ongoing feedback on the health needs of women, children, families, and communities, and the strengths and weaknesses of current systems serving these populations.

Whenever possible, the IL Title V builds upon existing networks and stakeholder groups to obtain feedback about the systems and services that impact women and families in Illinois.

**MCH Data Capacity and Infrastructure (Priority #10):**

Illinois developed SPM #5 to measure progress in improving data capacity over time. This measure considers 10 potential MCH data sources and whether the Title V epidemiology staff have direct access to these sources, whether the team conducted any specific analyses of these data files (beyond standard reporting requirements), and whether the findings were disseminated through presentations, reports, or other data products. A total score of 30 points is possible if all 10 data sources were available, analyzed, and had a related data product within one year. This SPM has shown steady improvement over the last three years, which coincides with the expanded epidemiology capacity of the Title V team.
The MCH data capacity score increased from 15 points in 2016 to 20 points in 2017 to 23 points in 2018. Specifically, the 2018 score can be broken down into 9/10 points for data access, 8/10 points for analysis, and 6/10 points for dissemination. SPM #5 will continue to be used to track progress in data capacity over time.

Additionally, the Title V epidemiology team tracks the specific data products that result from various projects and analyses. Dissemination of findings through these types of products is important for informing MCH practice in the state and promoting evidence-based decision making. Products that are counted may include fact sheets, data briefs, conference presentations, reports, or published manuscripts. The number of data products developed by Title V has risen over time, increasing from 14 products in 2016 to 17 products in 2017 to 21 products in 2018. During 2018, the 21 data products included: nine oral presentations at conferences, six posters at conferences, three data reports, two products, and one scientific manuscript. The products will continue to be tracked to demonstrate the value of the epidemiology team.

The IL Title V utilizes the following strategies to address the Cross-Cutting/Life Course Domain priority #10: strengthen capacity for data collection, linkage, analysis, and dissemination; improve MCH data systems and infrastructure:

**MCH Data Capacity and Infrastructure (Priority #10):**

Illinois developed SPM #5 to measure progress in improving data capacity over time. This measure considers 10 potential MCH data sources and whether the Title V epidemiology staff have direct access to these sources, whether the team conducted any specific analyses of these data files (beyond standard reporting requirements), and whether the findings were disseminated through presentations, reports, or other data products. A total score of 30 points is possible if all 10 data sources were available, analyzed, and had a related data product within one year. This SPM has shown steady improvement over the last four years, which coincides with the expanded epidemiology capacity of the Title V team. The MCH data capacity score increased from 15 points in 2016 to 27 points in 2019. Specifically, the 2019 score can be broken down into 9/10 points for data access, 9/10 points for analysis, and 9/10 points for dissemination. SPM #5 will continue to be used to track progress in data capacity over time.

A. Develop data products and reports for a variety of audiences.

The MCH epidemiology team conducted many analytic projects to inform decision-making in the state, particularly as related to the 10 Title V priorities. Some of the analyses and epidemiologic studies completed during 2019 included the topics of:

- Predictors of risk-appropriate care for very preterm infants
- Barriers to maternal transport for very preterm deliveries
- Neonatal outcomes associated with risk-appropriate care
- Teen births
- Perinatal depression
- Pregnancy-associated and pregnancy-related mortality
- Postpartum contraception use
- Neonatal abstinence syndrome
- Opioid-related mortality among women of reproductive age
- Mental health and substance use hospitalizations
- Childcare as a social determinant of maternal health services

The Title V epidemiology team tracks the specific data products that result from various projects and analyses. Dissemination of findings through these types of products is important for informing MCH
practice in the state and promoting evidence-based decision making. Products that are counted may include fact sheets, data briefs, conference presentations, reports, or published manuscripts. The number of data products developed by Title V has risen over time, increasing from 14 products in 2016 to 23 products in 2019. During 2019, the 23 data products included:

- 9 oral presentations at conferences
- 2 posters at conferences
- 3 webinar presentation
- 1 presentation at a state meeting
- 5 data reports
- 3 scientific manuscripts

The five data reports produced during 2019 were:

- Final report on ePeriNet data system evaluation for maternal/infant transport data (used for internal planning purposes)
- Data report on postpartum contraception use using PRAMS data
- Data sheet series covering the Title V national outcome and performance measures by topic area (created during needs assessment to inform Title V priority selection and action plan development)
- Report on findings from adolescent health focus groups with school-based health centers (created during needs assessment to inform Title V priority selection and action plan development)
- MCH Family Council Listening Sessions report (created during needs assessment to inform Title V priority selection and action plan development)

In addition to IDPH data report, CDPH publishes data on www.healthychicagobabies.org through their Title V mini-grant the use of data sets received from IDPH. The following data points are currently reported: birth rate, teen birth rate, infant mortality rate, low birthweight, preterm delivery, and first trimester prenatal care.

B. Present findings of epidemiologic and other studies conducted by Title V and its partners at state and national meetings and conferences; publish in peer-reviewed journals or state morbidity and mortality review.

The IL Title V well represented the work of Illinois at various state and national meetings during 2019. MCH staff members, fellows, and interns were accepted for nine oral presentations and two poster presentations at state/national conferences, including the Illinois Women and Families Health Conference, Association of Maternal and Child Health Programs (AMCHP) annual conference, Council of State and Territorial Epidemiologists Annual Conference, Prevent Child Abuse Illinois state conference, National Governor’s Association conference, Rush University Medical Center’s perinatal health conference, and the MMRIA User Meeting hosted by CDC. Topics for these presentations included maternal mortality, perinatal depression, childcare as a social determinant of maternal health, and trauma-informed health education in Illinois’ women’s prisons.

In addition, during 2019, Illinois Title V epidemiology staff were co-authors on three manuscripts that were accepted for publication in peer-reviewed journals. The lead author on each of these papers were interns or fellows who had worked with IDPH on their projects. Citations for the papers are included below (with Title V staff bolded and intern/fellow author underlined):


C. **Develop and implement data linkage plans for data sources relevant to MCH.**

Linkage of data systems has long been identified as a need to improve MCH surveillance, assessment, and evaluation, but few of the MCH datasets available to OWHFS are currently linked. For many years, IDPH Division of Vital Records did not have the staff resources to complete a match of the infant birth and death certificates while they shifted to new electronic databases. The infant birth-death match was resumed with the 2014 birth cohort. The availability of this linked data file allows for in-depth analyses of infant mortality that are essential for informing perinatal health activities. No other data linkages related to MCH data sources have been routinely implemented or used by Title V within the last five years.

The Title V epidemiology team continues to advance the development and use of linked MCH data systems through ongoing evaluation and validation. The CDC assignee conducts validation of the matched infant birth and death certificates each year as the vital records files are finalized. This involves using LinkPlus software to conduct probabilistic linkages and to search for matches not identified by the state’s automated vital records matching software, or for incorrect matches that need to be “unlinked”. Updated information is provided to IDPH Division of Vital Records, so they can improve their matching system. During FY2019, the matching process for the 2016 birth cohort was completed. This additional validation of the matching process has improved the matching rate for resident infant deaths from about 90% to about 99%. This will be an annual ongoing activity of the data team to ensure that high-quality matched infant birth and death records are available for detailed analyses of infant mortality.

During FY2019, the IL Title V obtained updated identifiable hospital discharge data for women and infants to link to other MCH datasets. The process of requesting and obtaining these files took multiple years but was finally successful during 2018. OWHFS will continue to build trust and collaboration with the discharge data steward (IDPH Division of Patient Safety and Quality) to demonstrate the value of the data linkages and to assure the security and appropriate use of the data. During FY2019, Title V epidemiology staff worked to link infant and maternal delivery hospitalization records to birth certificates for the 2015 and 2016 birth cohorts. These linkages will continue to be finalized and tested during FY20.

D. **Support efforts to sustain improvements in birth certificate accuracy through partnership with the ILPQC and IDPH Division of Vital Records.**

The CDC MCH Epidemiology Assignee serves on the data committee for ILPQC and assists with population-level data that shows the value and impact of state QI initiatives. She supports the sustainability phase of past initiatives, including the birth certificate accuracy initiative, which was implemented during 2014-2015. While most of the activities for this project are complete, during FY2019, the assignee did provide technical support in the development and revision of a manuscript that ILPQC submitted to the *Maternal and Child Health Journal* and the *Journal of Community Health* on the impact of the birth certificate accuracy initiative. The manuscript is under revision with a third journal and the hope is that it will be published in 2020, and no new activities are expected after that time.

E. **Partner with and support Illinois PRAMS to use innovative strategies for improving response rates.**
Illinois PRAMS and OWHFS collaborate to improve survey response rates, by using Title V funds to cover the cost of an increased Illinois PRAMS reward for respondents. Per established protocols, respondents previously received a small spiral bound note pad for completing the survey. To improve response rates, Illinois PRAMS sought funding from OWHFS in 2018 to provide a $15 gift card restricted to the purchase of diapers and baby wipes. The purpose of the new reward is to encourage selected respondents to complete the survey by being more appropriate to the time and effort involved in completing the survey. The reward change was implemented during April 2018 and is ongoing. Following the reward change, monthly response rates increased. Illinois PRAMS expected to continue being able to meet, and likely exceed, the minimum required response rate established by the Centers for Disease Control and Prevention (CDC).

F. Support the development and use of questions focused on the social determinants of health in state health surveys.

During April-December 2019, Illinois PRAMS included an opioid questionnaire supplement. The questions will collect information from recent mothers on their use and potential misuse of opioids. The PRAMS Director worked closely with Title V epidemiology staff in the application for this supplement funding and will continue to work with epidemiology staff in the analysis of data.

As a result of Illinois' participation in the national SDOH COIIN, Illinois drafted, and piloted survey questions related to the impact of childcare on health service utilization for women. Local clinical partners shared anecdotes of how women may cancel or delay appointments if they do not have someone to watch their child(ren), however, the national core and standard questions for PRAMS do not include questions specific to this topic. Title V staff and interns drafted seven questions on the impact of childcare on women's utilization of health services to mirror the structure of various existing multiple-choice PRAMS questions. Three federally qualified health centers (in northern, central, and southern Illinois) recruited a convenience sample of postpartum women with an infant up to 1 year of age to complete the survey and be interviewed to provide feedback on the questions. A total of 54 postpartum women were surveyed; 30% were non-Hispanic white, 63% were non-Hispanic black and 7% were Hispanic. Pilot participant feedback on the proposed survey questions was generally positive and indicated they were simple and easy to answer. The question that was easiest to understand included a yes/no answer and asked, “Have you ever had to reschedule or skip a healthcare visit for yourself because you had no one to watch your child(ren)?” and approximately 33% of pilot participants responded in the affirmative to this question. Similarly, 30% reported having to reschedule or skip a visit during their most recent pregnancy. Interviews revealed that social support and transportation greatly affected childcare options. This pilot project affirms that childcare is an important factor that influences women’s ability to receive health services. Population-based data is needed to quantify the full burden of this problem. The upcoming PRAMS phase 9 revision (likely in 2021-2022) offers an opportunity to revise the IL-PRAMS questionnaire and add new questions. The findings and feedback from this pilot will be shared with the Illinois PRAMS Steering Committee to inform its development of the Phase 9 questionnaire.

During 2019, Illinois developed a social determinants of health (SDOH) abstraction form to use in conjunction with maternal mortality reviews. The state SDOH-MMRC form is more detailed than the “social and environmental context” form within MMRIA and provides a structured way of assessing various domains of SDOH that related to maternal mortality. An OWHFS intern led the development and testing of this form during summer 2019. By fall 2019, the form was finalized and began being routinely collected on all deaths abstracted for review by the MMRC/MMRC-V. This information will be merged with other maternal death information to allow for detailed analysis of SDOH issues affecting maternal mortality.

G. Maintain and enhance ePeriNet data system for perinatal hospital reporting of quality and

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outcome data.

Title V supports the development and maintenance of the ePeriNet data system, which collects data to inform quality improvement work for the Illinois regionalized perinatal system. All birthing hospitals and administrative perinatal centers are required to enter information related to key maternal and infant quality and health outcomes, such as mortalities, transfers, and specific morbidities. For example, ePeriNet is the data system that collects the VPT review forms to track barriers to antenatal maternal transport. During FY2018-2019, the CSTE Fellow conducted an evaluation of the infant and maternal transport forms in ePeriNet to consider how to improve the system’s functions as a surveillance system of sentinel perinatal events. She presented the findings of the evaluation to Title V leadership in 2019 and including her specific recommendations for improvements. While some of these recommendations involve much larger changes to the way that data are collected in ePeriNet, there were several smaller improvements that were made to ePeriNet during 2019. These changes included: requiring a response for key fields (e.g., generating an error if this field is left blank), incorporating data validation criteria into numeric and date variables (e.g., not allowing alpha characters in a numeric field), and editing drop-down and check-box responses to better align with reporting needs. In addition, the ePeriNet vendor created a basic “dashboard” page within the system so that APCs and hospitals can view quick snapshots of their aggregate data over time.

H. Maintain the CDC MCH epidemiology field assignee position to strengthen scientific leadership and enhance data capacity and infrastructure.

Illinois continued to serve as an assignment site for a CDC field assignee in maternal and child health epidemiology, Amanda Bennett, PhD, MPH. Dr. Bennett began her CDC assignment with IDPH in December 2014, after already working with Illinois Title V in various capacities since 2007. Her role is to provide technical assistance and scientific leadership to the Illinois MCH programs by conducting research and surveillance; building MCH epidemiology capacity; and providing information to support program development, management, evaluation, and resource allocation. During FY2019, she provided input into the performance measurement structure for Illinois Title V, designed and implemented epidemiologic studies, led the maternal mortality surveillance and review processes, and mentored interns, fellows, and other IDPH epidemiology staff. She presented at national conferences and state meetings and provided technical assistance to various state advisory committees.

I. Mentor graduate student interns and fellows in epidemiology.

During FY2019, OWHFS continued to host a Council of State and Territorial Epidemiologists (CSTE) Applied Epidemiology Fellow in MCH epidemiology, Ms. Ashley Horné, MSPH. Ms. Horne was mentored by Dr. Bennett and by Dr. Jane Fornoff, epidemiologist and manager for the Adverse Pregnancy Outcomes Reporting System (APORS; state birth defects registry). Her major projects focused on maternal morbidity and mortality, neonatal abstinence syndrome, and evaluating the state perinatal hospital reporting database (ePeriNet). She helped to improve MCH epidemiologic capacity through program data analysis, needs assessment, surveillance, data linkage, data dissemination/translation, and grant writing. She completed her fellowship in April 2019 and moved to external employment in women’s health research at a local university.

The IL Title V continues to support students seeking internships in maternal and child and/or epidemiology. OWHFS increased its epidemiology and research capacity by hosting nine students for various internships during 2019 (1 undergraduate students, 5 master’s students, 1 medical student, and 2 doctoral students). These students completed projects on a wide variety of topics, including social determinants of health, maternal mortality, family planning/contraception, the impact of childcare on women’s health, mental health and substance use among women, and adolescent health. They significantly contributed to the work of the health department through the development of 1 evaluation
plan, 3 data collection tools, 1 data linkage, 5 quantitative data analyses, 3 qualitative data analyses, and 2 formal data reports.

The CDC Assignee also served on the Scientific Oversight Committee for neonatology fellow conducting research on antenatal maternal transport and neonatal mortality among very preterm infants during 2019. As a result of this partnership, this fellow published a paper on neonatal mortality for very preterm infants in *JAMA Pediatrics*.

J. **Enhance training and workforce development opportunities for staff.**

Title V staff were encouraged to attend professional development activities and conferences as they were able. Staff members attended and/or presented at conferences such as the AMCHP annual conference, CSTE annual conference, Title V Federal-State Partnership meeting, and MMRIA User Meeting.

In addition, the IDPH-OWHFS hosted its annual Illinois Women and Families Health Conference in October 2019. Title V staff contributed to the planning of this conference, and all IDPH-OWHFS staff were expected to attend. Additionally, Title V epidemiology staff designed the conference evaluation survey, analyzed the survey data, and provided a report for the planning staff to help with future conference planning.

K. **Obtain technical assistance and epidemiologic support from the University of Illinois at Chicago Center of Excellence in Maternal and Child Health through an intergovernmental agreement.**

During FY2019, Illinois Title V continued its partnership with the University of Illinois at Chicago (UIC) Center of Excellence in Maternal and Child Health. Through an Intergovernmental agreement (IGA) enacted in 2013, UIC faculty, staff, and students provide assistance on analytic projects and represent MCH epidemiology at state workgroups and committees. The CDC assignee serves as the main coordinator and liaison for the collaborative projects between OWHFS and UIC. Dr. Bennett meets bimonthly with the UIC team to discuss project priorities, action steps, and progress on activities and provides feedback to UIC team on analytic plans, methodology, and data products.

During FY2019, UIC led the development and implementation of the Title V needs assessment for 2020. More details about the specific products resulting from this partnership are available in the needs assessment section.

L. **Provide epidemiologic technical assistance to, and collaborate with, other IDPH divisions, other state agencies, and external partners on data projects.**

During 2019, the CDC assignee continued to serve as data lead and provided analytic and technical assistance to the various workgroups of the Illinois CoiIN team by: 1) using provisional birth and infant death certificate data to calculate quarterly infant mortality and prematurity rates; 2) providing input into the design and interpretation of stakeholder surveys; 3) supporting evidence-based decision-making by analyzing relevant data from various data sources; 4) implementing a special study of very preterm infants to support the work of the Risk-Appropriate Care group.

Illinois Title V data staff also provide technical support to other state quality improvement initiatives, such as projects conducted in collaboration with the Illinois Perinatal Quality Collaborative (ILPQC). The CDC MCH Epidemiology Assignee serves on the data committee for ILPQC and assists with population level data that shows the value and impact of state QI initiatives. She supports the sustainability phase of past initiatives, and advises ILPQC on data interpretation, translation, and dissemination. For
example, in 2019, she provided data on opioid deaths among women of reproductive age to ILPQC for use in the Mothers and Newborns Affected by Opioids (MNO) initiative.

The Illinois Department of Public Health Office of Women’s Health and Family Services (OWHFS) and the Pregnancy Risk Assessment Monitoring System (PRAMS) project have a well-established, ongoing collaboration to assure the data collected by PRAMS assists in the efforts of OWHFS to support healthy pregnancies, improve birth outcomes, reduce infant mortality, and eliminate health disparities. Illinois PRAMS and OWHFS maintain an intra-departmental data use agreement allowing PRAMS data sets to be shared with OWHFS as soon as they become available. During the reporting period, the 2017 PRAMS data sets was released to OWHFS and used in policy and program planning.

Additionally, the Title V epidemiology team continues to build and develop relationships with other epidemiologists, data users, and data stewards at IDPH. During FY2019, OWHFS maintained access to key public health data sources in Illinois, such as vital records and hospital discharge. Through these relationship, Illinois Title V has access to population-based data to monitor the health of women, infants, children, and adolescents, and provide a mutual benefit in the analysis, data translation, and interpretation of findings.

Chicago-based epidemiology staff also attended a quarterly meeting of IDPH epidemiologists to learn about the epidemiologic work of other divisions and to partner on projects of mutual interest.

M. The UIC-DSCC will collaborate with the UIC School of Public Health’s Center of Excellence in MCH to analyze data related to CSHCN programs and services.

To support the Title V needs assessment of CYSHCN in Illinois, UIC-DSCC contracted with the UIC CoE-MCH in 2019 to design and conduct a survey of DSCC families on their experiences with UIC-DSCC care coordination programs focused on the six core outcomes for CSHCN systems. The Family Survey questions were constructed using the National Survey for Children’s Health (NSCH) to allow UIC-DSCC to compare its results to those of the NSCH results. The Family Survey also included open ended comments to capture additional input from the respondents.

The Family Survey was launched in April 2019. A total of 5,248 families were sent the survey, 2,927 families with known email addresses received a survey link and another 2,321 families were mailed the survey. Two reminder postcards were mailed, and the survey closed May 31, 2019. Eligible survey participants were those where the family of the youth spoke either English or Spanish, and where the youth in DSCC programs was younger than 18 years old by the time the survey period closed. A total of 1,005 survey responses were received (19% response rate) which provided a sampling error of ±2.4% at the 95% confidence interval. Black or African American and Hispanic children and youth, and children under the age of 6 were under-represented in the survey.

Survey results were compared to the NSCH on the following outcomes: (1) Families of CSHCN partner in decision-making regarding their child’s health; (2) CSHCN receiving coordinated and ongoing comprehensive care within a medical home; (3) Community-based services are organized so families can easily access them; (3) Families of CSHCN have adequate private and/or public insurance to pay for needed services; and (4) Youth with special healthcare needs receive the services necessary to make transitions to adult health care. More information about the family survey, its use in the Title V needs assessment, and the survey result is available in the Needs Assessment section of this report.

N. Implement the CDC Maternal Mortality Review Information Application (MMRIA) to collect standardized information on pregnancy-associated mortality.

In January 2019, after about one year of development by the Illinois Department of Information
Technology (DoIT), Illinois began to use a state-hosted MMRIA system. However, after only a few months of this system being live, Illinois paused data entry because of the announcement that CDC would be rolling out a centrally-hosted system and was encouraging all states to shift to that system. The CDC-hosted system will facilitate more regular and consistent system upgrades/changes, and will reduce the IT burden on states because they will not have to maintain their own individual systems. In late 2019, Illinois successfully onboarded to the CDC-hosted system. In 2020, Illinois DoIT transferred of previous MMRIA data to the state system, and new case data entry was resumed.
FY2021 IL Title V State Application Plan by Domain

After an extensive needs assessment process that included the review of IL Title V’s past priorities, strategies, programs and partnerships as well as feedback from its Advisory Council, IL Title V has adopted the priorities provided below in Figure 2. These priorities will guide IL Title V’s efforts to improve the health of women, children and families across Illinois for the next five years (FY2021 through FY2025). As noted in the Needs Assessment section of this document, three of these priorities are repeated and another three are slightly revised from FY2016-2020, and the remaining four priorities are new.

Figure 2. 2021-2025 Title V Priorities

Women/Maternal Health - Application Year

Illinois’ priority for the Women and Maternal Health Domain is:

- Assure accessibility, availability, and quality of preventive and primary care for all women, particularly for women of reproductive age (Priority #1)
- Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum (Priority #2)

Access, Availability and Quality for Women (Priority #1)

During FY21, IL Title V will utilize the following strategies to address Priority #1 - Assure accessibility, availability, and quality of preventive and primary care for all women, particularly for women of reproductive age:
A. Support the Illinois Healthy Choices, Healthy Future Perinatal Education Toolkit, which includes information and resources for providers of women during Preconception, Prenatal, Postpartum, and Interconception Care.

During FY21, EverThrive Illinois will maintain the Illinois Healthy Choices, Healthy Futures Perinatal Education Toolkit, developed for clinical providers as well as promote, update, and maintain the toolkit’s new website: http://healthychoiceshealthyfutures.org/.

B. Partner with the Illinois Department of Corrections (DOC) and two state women’s correctional centers to support ongoing health promotion activities for incarcerated women and staff training, and to ensure women and infants receive WIC services while residing in DOC facilities.

For FY21, OWHFS will continue to partner with the Illinois Department of Corrections to offer health education to incarcerated women, provide training to corrections staff, help stock women’s health supplies (such as breast pumping supplies), and work closely with corrections staff to meet the health needs of women in Illinois prisons. The program will continue to implement the previously adopted evaluation plan which will demonstrate the value and impact of these efforts. Title V will specifically support this work by conducting the evaluation (epidemiology team), providing birth simulation training to prison staff, and providing information and support to corrections officers working with women who are pregnant, postpartum, or parenting. Future training programs are being formulated based on the feedback provided by the clinical staff at both correctional centers.

Additionally, OWHFS will continue to teach health education sessions using the Helping Women Recover, Beyond Trauma and Life Smart for Women curricula. Training opportunities for prison health care staff will continue to focus on comprehensive care for their expectant mothers, trainings on trauma and Adverse Childhood Experiences (ACEs), as well as better understanding of and specifically recognizing the unique health care needs of their LGBTQ population. An additional training programming will include a full simulation of a maternal transport team from the Level III Administrative Perinatal Center coming to pick up a patient in active labor. This simulation will allow corrections security to test the “lock-down” process for active labor patients while allowing EMS to enter and treat a woman and neonate in the pregnancy wing or health care wing.

The IDPH southern perinatal nurse will continue to collaborate with the Administrative Perinatal Center, South Central Illinois, other OWHFS staff, and correctional centers to assist in the process for women receiving maternal-fetal medicine consultations.

C. Implement well-woman care mini-grants to assist local entities in assessing their community needs and barriers; and develop and implement a plan to increase well-woman visits among women ages 18-44 years based on the completed assessment.

During FY19, IL Title V staff began planning for the well-woman care mini-grants, with the goal to provide funding to local organizations who work with women ages 18-44 to develop and implement a plan to positively impact the number of women seeking well-woman care. Using best-practice examples from other states, example activities were suggested, including using the CityMatCH Well-Woman Toolkit, providing education and training to women to increase health literacy, and developing local resource guides for where women could access care. For FY21, IL Title V will continue to support and implement the well-woman care mini-grants.

D. Partner with the University of Illinois at Chicago (UIC) Center for Research on Women and Gender to implement a program at two clinic sites to expand the capacity of Illinois health care providers to screen, assess, refer and treat pregnant and postpartum women for depression and related behavioral health disorders.

During FY21, IL Title V will continue to partner with the UIC-CRWG as it pilots a program at two clinic
The goals of the program are to increase the capacity of perinatal providers to screen, assess, refer, and treat behavioral health disorders, and to increase awareness of and access to affordable and culturally appropriate services. Through these efforts, IL Title V and UIC-CRWG hope to improve the mental health and well-being of pregnant and postpartum women and their infants in the State of Illinois.

E. Support the Chicago Department of Public Health (CDPH) efforts to foster, partner, and collaborate with organizations and agencies providing male and partner involvement programs.

For FY21, CDPH will seek to engage male and partner involvement in its efforts to increase women’s early entry into prenatal care. These efforts will include leveraging relationships with organizations and agencies that target the same population. IL Title V will support CDPH’s efforts through the Title V mini-grant.

Comprehensive and Informed System (Priority #2)

During FY21, IL Title V will utilize the following strategies to address Priority #2 - Promote a comprehensive, cohesive, and informed system of care for all women to have a healthy pregnancy, labor and delivery, and first year postpartum:

A. Convene and facilitate state Maternal Mortality Review Committees (MMRC and MMRC-V) to review pregnancy-associated deaths and develop recommendations to improve quality of maternal care as well as reduce disparities and address social determinants of health.

During FY21, Illinois will continue its process for identifying pregnancy-associated deaths in Illinois and assuring reviews by the state’s two maternal mortality review committees. MMRC will continue to review every potentially pregnancy-related death and MMRC-V will continue to review violent pregnancy-associated deaths due to suicide, homicide, or drug overdose. The revised processes developed during 2017 will continue to be implemented with an informal quality improvement lens applied; as IDPH continues to try new processes, small changes over time will be implemented and tested to ensure that the process is as smooth and effective as possible.

It is expected that OWHFS will publish its second Illinois Morbidity and Mortality Reports in FY21, with additional reports in subsequent years of the 5-year Action Plan (2021-2025). These reports will include findings from the state reviews, such as demographic disparities, leading causes of death, factors contributing to deaths, preventability, and committee recommendations. As was done in the past, IDPH will pursue multiple methods for disseminating the report and present the findings to relevant groups around the state and nation.

In FY20, OWHFS successfully applied for the CDC-RFA-DP19-1908 funding opportunity entitled Preventing Maternal Deaths: Supporting Maternal Mortality Review Committees. This is a five-year grant for the 2020-2024 cycle. During FY21, the IL Title V staff seeks to implement interventions to address maternal mortality which includes hosting a statewide maternal health summit, convening stakeholders, including community partners, to create a multi-pronged strategic plan to improve maternal health based on the recommendations from the MMRCs.

B. Partner with the statewide Severe Maternal Morbidity (SMM) Review sub-committee to develop recommendations for standardizing and improving hospital-level SMM case reviews across Illinois' Regionalized Perinatal System.

The University of Illinois at Chicago’s Center for Research on Women and Gender (UIC-CRWG) will continue its existing intergovernmental agreement to assist with the Severe Maternal Morbidity quality improvement activities, such as monitoring the data completeness and quality of SMM review forms submitted to the state perinatal hospital database and providing technical assistance to administrative perinatal centers (APCs) and birthing hospitals on how to improve reviews. UIC-CRWG staff will also
work with the data system developer to assure that data collection forms and indicators are clearly defined and to assure high quality data submission.

Additionally, the SMM Review Committee, which the UIC-CRWG helped establish help improve and standardize hospital-level reviews. It is expected that UIC-CRWG will continue to help facilitate the meetings, analyze decisions of the state-level committee, and take lead in helping the Committee create training materials, templates, and resource manuals, as needed, to improve the quality of the local reviews within hospitals and APCs.

C. Participate in and collaborate with the Illinois Maternal Health Task Force established through the I PROMOTE-IL program (HRSA Maternal Health Innovation Grant) to translate findings and implement recommendations from the Illinois MMRC, MMRC-V and SMM.

In FY19, The University of Illinois at Chicago (UIC) successfully applied for the HRSA Maternal Health Innovation Grant. The Innovations to ImPROve Maternal OuTcomEs in Illinois (I PROMOTE-IL) program will assist the State in collaborating with maternal health experts and optimizing resources to implement state-specific actions that address disparities in maternal health and improve maternal health outcomes. A key component of the I PROMOTE-IL grant is the Illinois Maternal Health Task Force. The Illinois Title V Director serves as co-Chair of the taskforce. This development is important because OWHFS/Title V is the primary lead for all maternal health activities in the state including Maternal Mortality and Severe Maternal Morbidity reviews. The participation and collaboration of the IL Title V ensures that the Task Force is fully integrated into the existing maternal health infrastructure in Illinois without duplication of efforts, as well as assist in the tracking of maternal health legislation at the state and federal level to inform additional policy solutions; and address identified gaps outside of Title V efforts.

During FY21, IL Title V will continue to participate in and collaborate with the I-PROMOTE-IL program and its Illinois Maternal Health Task Force, and the Title V Director will continue to serve as a co-chair for the Task Force.

D. Support and collaborate with the state-mandated Illinois Task Force on Infant and Maternal Mortality Among African Americans to assess the impact of overt and covert racism on pregnancy related outcomes, identify best practices and effective interventions, address social determinants of health, and develop an annual report with recommendations to improve outcomes for African American women and infants.


During FY21, IL Title V will support and collaborate with the Task Force on Infant and Maternal Mortality Among African Americans to review the impact of overt and covert racism on toxic stress and pregnancy related outcomes for African American women and infants in Illinois, and assist in the development of the annual report with recommendations of best practices and interventions to improve quality and safe maternal and infant care across Illinois.

F. Participate in state inter-agency committee efforts to improve Medicaid coverage and care coordination for pregnant and postpartum women by extending coverage from 60 days to 12 months postpartum, allowing managed care reinstatement within 90 days, and waiving hospital presumptive eligibility.

The federal Centers for Medicare & Medicaid Services (CMS) is currently reviewing an Illinois Continuity of Care & Administrative Simplification 1115 waiver application. The 1115 waiver request includes extending Medicaid postpartum coverage from 60 days to 12 months, which was included in the state’s budget implementation bill and signed into law with a January 1, 2020 effective date.

During FY21, OWHFS and IL Title V will continue to participate on the state inter-agency committee as it develops implementation, monitoring and evaluation plans regarding the extended coverage, continuous eligibility, reinstatement and waiver of hospital presumptive eligibility (HPE).

G. Convene and partner with key stakeholders to identify gaps in mental health and substance abuse services for women that include difficulties encountered in balancing multiple roles, self-care and parenting after childbirth; and leverage expertise to develop recommendations for system level improvements for Title V consideration and implementation.

During FY21, IL Title V will continue to partner with UIC-CRWG to improve the mental health and well-being of pregnant and postpartum women, and their infants, throughout Illinois. Activities will continue to focus on expanding the capacity of perinatal health care providers in Illinois to screen, assess, refer, and treat pregnant and postpartum women for depression and related behavioral health disorders, and to increase awareness of, and access to, affordable and culturally-appropriate services to pregnant and postpartum women and their infants in Illinois. Currently, the project targets obstetricians, gynecologists, nurse midwives, pediatricians, psychiatric providers, mental health care providers, social workers, and primary care providers in geographical areas serving disadvantaged women, including Cook County/Chicago and Peoria and surrounding communities in Peoria County (Providers). UIC-CRWG will continue to: (i) provide in-person workshop training and resources on screening, diagnosis, and referral for maternal depression and related behavioral disorders to Providers; (ii) provide real-time psychiatric consultation and care coordination for Providers; (iii) screen women for depression, anxiety, suicide risk, and substance use during the perinatal period using Computerized Adaptive Testing (CAT); (iv) increase access to depression prevention and treatment for medically underserved women using a telehealth intervention; (v) increase access to substance use treatment for pregnant women; and (vi) develop recommendations for disseminating and implementing the project components statewide. UIC-CRWG will also coordinate with the Health Care Alternative Systems program at the Illinois Department of Human Services, which runs a perinatal depression screening and referral program, in an effort to reduce duplication and/or fragmentation of services.

H. Assess, quantify and describe the impact of childcare on prenatal, intrapartum and postpartum care in Illinois, and develop optional strategies and approaches, and can be implemented in clinic and hospital settings.

Although the Social Determinants of Health Collaborative, Improvement, and Innovation Network (CoIIN) will end in FY20, IL Title V will continue to assess the need for ‘emergency’ childcare in circumstances related to obtaining perinatal care (prenatal appointments, labor and delivery/hospitals) for women/parents and developing women/family-friendly childcare strategies for prenatal and perinatal providers.

I. Support the Illinois Perinatal Quality Collaborative (ILPQC) in implementation of as it seeks to implement obstetric and neonatal quality improvement projects initiatives in birthing hospitals.

During FY21, the regionalized perinatal program will continue to disseminate the toolkit and other related training materials to birthing hospitals throughout Illinois. Hospitals will be encouraged to provide annual training on obstetric hemorrhage to all hospital staff that interact with pregnant/postpartum women.
ILPQC will continue to support hospital implementation of Mothers and Newborns affected by Opioids (MNO) OB & Neonatal Sustainability. More specifically, ILPQC will provide support for hospital teams to implement strategies for culture change and improve patient care.

During FY21, IL Title will partner with ILPQC on two additional initiatives: (1) The OB Promoting Vaginal Birth (PVB) QI Initiative; and (2) the Neonatal Babies Antibiotic Stewardship Improvement Collaborative (BASIC) QI Initiative.

J. **Support the Perinatal Depression Program which provides 24-hour telephone consultation for crisis intervention for women suffering from perinatal depression.**

During FY21, IL Title V will continue to provide financial support and program monitoring to the Perinatal Depression Hotline, as it continues provide assistance to women and families across Illinois

**Challenges and Emerging Issues**

A development occurring in smaller urban or rural areas in other states, Illinois is beginning to experience a significant challenge in the closing of hospitals or the specific elimination of obstetrical services within hospitals. IDPH is in discussions with key partners to develop a study group to better understand the specific factors leading to the decisions to close these units and develop plans to prevent any further closures.
Perinatal/Infant Health - Application Year

Illinois’ priority for Infant and Perinatal Health Domain is:

- Support healthy pregnancies and improve birth and infant outcomes (Priority #3)

During FY21, IL Title V will utilize the following strategies to address Priority #3 - Support healthy pregnancies and improve birth and infant outcomes:

A. Maintain a strong system of regionalized perinatal care by supporting perinatal network administrators and outreach/education coordinators and identifying opportunities for improving the state system.

During FY21, the 10 APCs will have an active role in several IDPH priority activities, including standardizing M&M case reviews, messaging on postpartum warning signs, educating emergency medical services (EMS) providers and non-birthing hospitals for emergency perinatal care to lower very pre-term birth deliveries outside a Level III facility, supporting ongoing simulations for obstetrical hemorrhage at birthing hospitals to prevent maternal morbidity and mortality, and neonatal resuscitation program education provided to birthing hospital clinicians to assist with the understanding of stabilization for neonates. The two IDPH perinatal nurses will continue to provide site visits and attend morbidity and mortality reviews at the hospitals. In addition, IL Title V will collaborate with birthing hospitals to provide education on important topics such as reducing several maternal morbidities in women with severe hypertension and fundamentals of fetal monitoring.

It is anticipated that OWHFS, IL Title V and the Illinois Perinatal Advisory Committee (PAC) will complete the drafting the new administrative rules regarding the Levels of Cares. Once the OWHFS has a completed draft of the rule language, the draft will be shared widely with birthing hospitals and stakeholders across the state for input. Once the feedback is reviewed and incorporated as necessary, OWHFS will submit the document the IDPH rulemaking process.

B. Implement surveillance systems to assess the impact of COVID-19 on pregnant women and neonates, including use of CDC’s COVID-19 pregnancy module and development of system to track universal testing of pregnant women admitted for labor and delivery.

During FY21, IL Title V will support sentinel surveillance of COVID-19 among women presenting for labor and delivery as an indicator for “Restore Illinois” (governor’s re-opening plan) by collaborating with birthing hospitals to implement and maintain universal testing among pregnant women presenting for labor and delivery; collecting supplemental data on women with lab-confirmed nCOV infection during pregnancy; and use all data to monitor transmission rate in Illinois population, inform movement between phases of re-opening and measure indirect effect of COVID-19 on maternal and child health.

C. Support the Fetal and Infant Mortality Review (FIMR) program that identifies factors that contribute to fetal and neonatal loss and subsequent adverse pregnancy outcomes and develops recommendations to improve quality care as well as address social determinants of health.

The Fetal Infant Mortality Review (FIMR) initiative is a nationwide systems strategy supported by the American College of Obstetricians and Gynecologists (ACOG) to identify non-medical factors that contribute to fetal and neonatal loss and subsequent adverse pregnancy outcomes. The goals include eliminating disparities in perinatal, infant, and maternal health; and directing resources and proposing interventions to improve access to, utilization of, and full participation in comprehensive perinatal and women's health services, particularly for women at higher risk for poor health outcomes. Beginning in
FY20, the FIMR was officially transferred for DHS to IDPH for administration and monitoring.

During FY21, Title V will continue to support the existing FIMR in Illinois and will explore opportunities to support additional FIMRs in Illinois that implement a program that aligns with objectives set by the national FIMR program.

D. Support the Illinois Perinatal Quality Collaborative (ILPQC) as it seeks to implement obstetric and neonatal quality improvement projects initiatives in birthing hospitals (Same as strategy 2-I)

This is the same as strategy 2-I. Information about this activity is available in the narrative for the Women’s/Maternal Health Domain

E. Convene partners to support statewide efforts to improve breastfeeding outcomes and reduce disparities.

The OWHFS is participating on a collaborative project known as the Illinois State Physical Activity and Nutrition Program (ISPN) which began in early 2019. This project aims to build on the significant accomplishments made already in physical activity and nutrition policy, systems, and environmental change. The purpose of this collaborative program is to reduce chronic disease and increase the health and well-being of Illinoisans by reducing disparities. The collaborative projects most aligned with IL Title V activities focuses on increasing the number of places (e.g., pediatric/family practices, WIC sites) that implement supportive breastfeeding interventions. IL Title V will support future pending programs that focus on establishing a statewide learning collaborative as well as providing training and support for local health departments which may include scholarships for WIC staff to become certified lactation consultants.

For FY21, IDPH will continue to partner with such organization as ILPQC and the Administrative Perinatal Centers to explore opportunities to educate moms with opioid use disorder about safe breastfeeding practices, as well as education around pregnancy and opioid use.

Illinois will continue to monitor the number of Baby-Friendly facilities and the proportion of births occurring in these facilities.

F. Partner with the Illinois Department of Corrections (DOC) and two state women’s correctional centers to support ongoing health promotion activities for incarcerated women and staff training, and to ensure women and babies receive WIC services while residing in DOC facilities. (Same as strategy 1-B)

This is the same as strategy 1-B. Information about this activity is available in the narrative for the Women’s/Maternal Health Domain.

G. Support and collaborate with the Illinois Task Force on Infant and Maternal Mortality Among African Americans to assess the impact of overt and covert racism on pregnancy related outcomes, identify best practices and effective interventions, address social determinants of health, and develop an annual report with recommendations to improve outcomes for African American women and infants. (Same as strategy 2-D)

This is the same as strategy 2-D. Information about this activity is available in the narrative for the Women’s/Maternal Health Domain.

H. Provide support to pregnant women at risk for poor birth outcomes through an array of case management and home visiting programs through the Illinois Department of Human Services
IL Title V will support MIECHV in its effort to serve pregnant women at risk for poor birth outcomes through an array of case management and home visiting programs through the Illinois Department of Human Services (DHS) Maternal, Infant and Early Childhood Home Visiting (MIECHV) program. IL Title V will also work with DHS to ensure DHS programs align with Title V priorities.

I. **Support the Chicago Department of Public Health (CDPH) in implementation of Family Connects Chicago to ensure nurse home visits for all babies and parents immediately following birth and linkage to a network of community supports to assist with longer term, family identified needs.**

During FY21, the Chicago Department of Public Health (CDPH) will use its MCH Mini-Block Grant to develop a pilot project of Illinois Family Connects at specific Chicago hospitals. Illinois Family Connects will implement a system of coordinated perinatal referral that uses universal nurse home visiting to identify the needs of families with newborns and connect them to appropriate supports and services. While Family Connects initially engages with mom and partner, the services will address the entire family, including other children.

Through the Title V mini-grant, CDPH will continue to address the needs of highest risk population of children. These infants will be identified in the Adverse Pregnancy Outcomes Reporting System (APORS) and others that must be enrolled in the DHS High-Risk Infant Follow-up Program.

**Challenges and Emerging Issues**

A development occurring in smaller urban or rural areas in other states, Illinois is beginning to experience a significant challenge in the closing of hospitals or the specific elimination of obstetrical services within hospitals. Ensuring timely access to appropriate levels of obstetrical care is a key priority of Title V. In FY21, IDPH will work with key partners to develop a study group to better understand the specific factors leading to the decisions to close these units and develop plans to prevent any further closures.
Child Health - Application Year

Illinois’ priority for the Child Health Domain is:

- Strengthen families and communities to assure safe and healthy environments for children of all ages (Priority #4)

During FY21, the IL Title V will utilize the following strategies to address Priority #4 - Strengthen families and communities to assure safe and healthy environments for children of all ages:

**Strengthen families and communities to assure safe and healthy environments for children of all ages:**

**A. Participate on the Illinois Early Learning Council to facilitate coordination between early childhood systems and assure that health is recognized as an integral component of improving children’s educational outcomes.**

The Early Learning Council, a public-private partnership was created to strengthen, coordinate and expand programs and services for children, birth to five, throughout Illinois. During FY21, the IL Title V Director will continue to participate on the Council as well as participate on the Illinois Home Visiting Task Force, which is a standing committee of Illinois’ Early Learning Council coordinated by the Ounce of Prevention Fund. This task force consists of approximately 200 members representing state agencies and private sector health, early childhood, and child welfare organizations, as well as providers, researchers, and advocates. The task force works with the Governor’s Office of Early Childhood Development to continue to advance the quality, quantity, and coordination of home visiting services across the funding streams and relevant departments and serves as the strategic advisory body for the MIECHV grant.

**B. Collaborate with home visiting programs, including the MIECHV program and early childhood providers, to encourage alignment of activities.**

During FY21, IL Title V will continue to broaden collaboration and align priorities with MIECHV and other home visiting programs in the state. Throughout FY21, IL Title V will actively work to ensure the MIECHV leadership and evaluators are engaged in the IL Title V programmatic workgroups as well as any HRSA Technical Assistance workshops of interest.

In addition, Title V will explore with MIECHV opportunities to leverage the partnership to improve the systems of care for women and children across Illinois. Specifically, the two entities will explore opportunities to train and educate home visitors about maternal morbidity and mortality (e.g. postpartum warning signs) and to use their existing community networks to promote positive messaging about women’s health and pregnancy. IDPH will also seek MIECHV’s input on areas in which IDPH and Title V should be trained to better assist MIECHV in its mission and vision.

Another noteworthy activity for FY21 involves IL Title V continuing to support and promote the Illinois Public Health Institute on the implementation of the Illinois State Physical Activity and Nutrition Program (ISPAN). The ISPAN includes activities to improve community supports for breastfeeding, including developing learning collaboratives for home visiting staff working in county health departments in order to improve duration of breastfeeding in rural, low-income, and non-Hispanic black communities.

**C. Convene partners to develop administrative rules and coordinate implementation of a new state law requiring social/emotional screening during school physicals.**

During FY21, it is anticipated that the new rules will be adopted, and the school health form revised accordingly. Activities will then include dissemination of changes to partners, coordinate implementation in the School Health Centers, and provide training and technical assistance to school nurses and other partners through the School Health Program.
D. Identify gaps in mental health programs and resources for Illinois children; develop partnerships with and within organizations focused on improving mental health among children and adolescents; and support the implementation of mental wellness programs that facilitate system level improvements as well as address social determinants of health.

IL Title V is invested in the health and wellness of all Illinois youth. Recent legislation requires essential mental health services within the certified School-Based Health Centers in Illinois; however, child and adolescent mental health is an area that necessitates more considerable attention, especially given the COVID-19 Pandemic. During FY20, two MCH Title V interns provide OWHFS a high-level overview of current mental health resources and programs within School-Based Health Centers, clinics, local counties, and organizations throughout Illinois which include constructive interviews with key informants. They identified key programs and gaps and provided recommendations. This information help as IL Title V convenes key stakeholders to explore the opportunities available to leverage and/or develop new initiatives to address child and adolescent mental health.

E. Certify and support school-based and school-linked health centers to expand access to primary health care, mental health, and oral health services for Illinois children and adolescents.

The School Health Program will continue to provide funding for School-Based Health Centers in FY21. A school-based health center improves the overall physical and emotional health of students, including underserved racial and ethnic populations, by promoting healthy lifestyles and by providing available and accessible preventative health care when it is needed. Health centers will continue to provide routine medical care to students enrolled in designated schools who have obtained written parental consent or who are otherwise allowed by law to give their own consent. Each regular clinic user undergoes an age-appropriate health risk assessment and receives related age-appropriate anticipatory guidance, treatment, or referral in response to findings. Each local advisory board decides whether other services (dental, mental health, drug and substance abuse counseling, and contraceptive services) will be provided on-site or by referral. Students in need of care beyond the scope of that offered at the health center are referred to specialists as needed.

The School Health Program will continue to increase awareness, knowledge, competency, and alignment in suicide prevention, assessment, and treatment for school and school health center personnel.

IL Title V will continue to provide funding for a Graduate Student Intern to assist with updating and maintaining the database and creating state-level reports.

F. Collaborate on with organizations and programs addressing the impact of Adverse Childhood Experiences (ACE) and toxic stress on children and adolescents' mental and physical health and throughout their life course.

During FY21, IL Title V will convene key stakeholders to identify opportunities for initiatives that will increase system capacity and capabilities to address ACE and toxic stress. IL Title V will make a concerted effort to ensure that families and other community leaders are included in discussions and program planning.

School Health as a Child Health Strategy

While not specifically mentioned during the narrative portion of the Child Health Domain, the IL Title V supports the certification and maintenance of high-quality school-based health centers. This includes provision of routine education and workforce development opportunities to Illinois school health nurses to support child health. Specifically, 41 of the 66 school-based health centers statewide are located in or provide services to elementary and middle school populations. To reduce duplication, the detailed efforts of the School Health Program are listed within the Adolescent Health Domain.
Adolescent Health - Application Year

Illinois’ priorities for the Adolescent Health Domain are:

- Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors (Priority #5)

During FY21, the IL Title V will utilize the following strategies to address Priority #5 - Assure access to a system of care that is youth-friendly and youth-responsive to assist adolescents in learning and adopting healthy behaviors:

A. Facilitate the Illinois Adolescent Health Program (AHP) to increase adolescents’ access to preventive and primary through adolescent-friendly clinics that provide comprehensive well-care visits, address behavioral, social, and environmental determinants of health.

The Adolescent Health Initiative was first funded in FY19 and provided grants to 12 entities, including local Health Departments and organizations to support the local implementation of strategies and support to increase the percentage of adolescents who received preventive and primary health care. The Illinois Chapter of the American Academy of Pediatrics to continue to develop and provide training and support for healthcare providers to expand adolescent-friendly healthcare services. Methods used by local organizations span from providing more youth friendly waiting areas, social media campaigns, conducting youth focus groups, to various modes of outreach and education.

During FY21, IL Title V will continue to implement the Adolescent Health Program (AHP) grant. Continuing this funding opportunity allows the IL Title V to better assess if the approaches taken by the grantees have increased adolescent well care visits within the grantee’s local communities and determine which approaches can be expanded statewide.

B. Collaborate with the Illinois Chapter of the American Academy of Pediatrics to encourage providers to adopt Lesbian, Gay, Bisexual and Transgender and adolescent-friendly services and spaces.

During FY21, ICAAP will continue to develop and share educational content and useful tools for increasing well-visits via social media, to their membership, and to the grantees of the Adolescent Health Initiative. In addition, ICAAP will continue host and facilitate the learning collaborative for the Adolescent Health Initiative grantees. It is expected that the content and tools will include an emphasis on adopting Lesbian, Gay, Bisexual and Transgender adolescent-friendly services.

C. Participate on and collaborate with the statewide Adolescent Suicide Ad Hoc Committee to develop strategic plan to reduce suicide ideation and behavior among youth in Illinois.

During FY21, IL Title V staff will continue to participate on and collaborate with the statewide Adolescent Suicide Ad Hoc Committee to develop strategic plan to reduce suicide ideation and behavior among youth in Illinois.

IL Title V funds will support a graduate intern position within IDPH Injury and Violence Prevention (IVPP) Program to facilitate adolescent suicide prevention activities. Activities are guided by Title V and IVPP staff, in collaboration with the Illinois Suicide Prevention Alliance Adolescent Suicide Prevention Ad Hoc Committee.

Additionally, IL Title V will continue to require school-based health centers to increase alignment in suicide prevention and response between schools and school health centers through collaboration on suicide protocol development. Centers will report the status of affiliated schools’ suicide protocols.
(adopted protocol, draft, none); engage with school administration and staff to develop new protocols or adapt an existing protocol to specifically mention school health staff, resources, and the involvement of the school health center within protocol; identify appropriate professionals who should be trained in identifying and responding to persons at risk of suicide; identify evidence-based training and tools and develop training plans and schedules; provide training to appropriate professionals in identifying and responding to persons at risk of suicide; and adapt training plans and schedules as needed to incorporate additional staff or activities

D. Identify gaps in mental health programs and resources for Illinois children; develop partnerships with and within organizations focused on improving mental health among children and adolescents; and support the implementation of mental wellness programs that facilitate system level improvements as well as address social determinants of health. *(Same as strategy 4-D)*

*This is the same as strategy 4-D. Information about this activity is available in the narrative for the Child Health Domain.*

E. Certify and support school-based and school-linked health centers to expand access to primary health care, mental health, and oral health services for Illinois children and adolescents. *(Same as strategy 4-E)*

*This is the same as strategy 4-E. Information about this activity is available in the narrative for the Child Health Domain.*

F. Increase awareness among health providers, families, communities and state systems about the impact of Adverse Childhood Experiences (ACE) and toxic stress on children and adolescents’ mental and physical health and throughout their life course. *(Same as strategy 4-F)*

*This is the same as strategy 4-F. Information about this activity is available in the narrative for the Child Health Domain.*

G. Support the implementation of the Chicago Healthy Adolescents and Teens (CHAT) program to improve sexual health education, sexually transmitted infections (STIs) screening and linkage to health care services.

During FY21, the Chicago Department of Public Health (CDPH) will continue to receive funding to implement the Chicago Healthy Adolescents & Teens (CHAT Program) to improve access to and coordination of school health services, linkage to medical homes, and access to adolescent sexual and reproductive health. A challenge for CDPH has been maintaining consistent funding for evaluation of CHAT and the IL Title V intends to consult with CDPH to see what support our epidemiology/data staff can provide.
Children with Special Health Care Needs - Application Year

Illinois’ priorities for the Children and Youth with Special Health Care Needs Domain are:

- Strengthen transition planning and services for adolescents and young adults, including youth with special health care needs. (Priority #6)
- Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs (Priority #7)

Transition (Priority #6)

During FY21, UIC-DSCC will utilize the following strategies and activities to address Priority #6 - Strengthen transition planning and services for adolescents and young adults, including youth with special health care needs:

A. Develop and implement a youth transition council.

For FY21, UIC-DSCC will begin developing a youth transition council. It is expected that the council will be fully developed and implemented by FY22.

B. Promote public education on transition services through use of social media and outreach presentations at community organizations.

For FY21, in order to increase awareness about transition services available in Illinois, UIC-DSCC will develop and disseminate educational materials through use of social media and outreach presentations at community organizations. Educational topics will include adolescent accountability and wellness through social media channels.

Additionally, UIC-DSCC will develop educational resources with a youth focus to provider practices across Illinois.

C. Implement a transition curriculum for youth and caregivers; and improve linkage to online guardian resources.

For FY21, UIC-DSCC will be in the process of identifying or developing a transition curriculum tailored to youth and caregivers. The curriculum will highlight the need for independence and empowerment. UIC-DSCC intends to leverage the expertise of the members of the Youth Transition Council once it is established. The Council will assist in finalizing the curriculum and its dissemination which will include an online component. UIC-DSCC anticipates implementing a curriculum by FY24.

D. Partner with health care providers to educate and support practice initiatives focused on preparation for transition to adulthood, including providing technical assistance to practices on using the 6 Core Elements of Transition 3.0 Toolkit for Providers, and developing youth-focused educational resources for provider practices.

During FY21, UIC-DSCC and IL Title V will continue to support Illinois School Based Health Centers as they monitor their transition activities regarding youth and young adult clients 14 years of age and under. In addition, to tracking and monitoring youth, SBHC will be implored to conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth their needs
and goals in self-care.

UIC-DSCC will provide technical assistance to provider practices using the Toolkit to improve transition readiness.

E. **Partner with state Medicaid agency, Medicaid Managed Care Organizations, Medicaid waiver operation programs, and/or private insurance providers to provide education and recommendations on practices pertaining to preparation for transition to adulthood.**

During FY21, UIC-DSCC will continue implementing its Connect Care Program. This program provides care coordination for children who were previously served by DSCC’s Core Program, and who are now enrolled in one of 6 Medicaid Managed Care Organizations who DSCC will contract with to provide care coordination. The Connect Care Program will be funded by reimbursement from the Medicaid Managed Care Plans.

F. **Co-sponsor the annual state Transition Conference and ensure the participation of UIC-DSCC youth and families in the conference and in conference planning.**

During FY21, UIC-DSCC will continue to participate in the planning and hosting of the annual Transition Conference in collaboration with key state partners. The conference provides an opportunity for physicians and other health care professionals, families, transition age youth, care coordinators, school staff, vocational specialists, and community providers to receive up-to-date information on all aspects of transition. UIC-DSCC staff will continue to serve on the conference steering committee, coordinate the health care track, and present workshops.

G. **Assist medically eligible CYSHCN, their families, and their providers with the transition to adult health care. Ensure person-centered transition goals are included in plans of care for participants between the ages of 12 and 21.**

During FY21, UIC-DSCC will continue to train staff on assessing transition readiness, specifying transition goals in the care plan, following-up with youth and families, and advocating with providers. UIC-DSCC will use a continuous quality improvement approach to strengthen assessment, planning, and plan implementation for CYSHCN participating in its Core and Home Care Programs. UIC-DSCC will also continue to require staff to provide a transition related goal in the person-centered care plan for all individuals enrolled in any of UIC-DSCC’s care coordination programs. UIC-DSCC will monitor this activity through its record review process and results will be available in the UIC-DSCC Scorecard.

H. **Continue participation in the Big 5 CYSHCN State Collaborative that seeks to identify and adopt common population health approaches for CYSHCN for all state participants.**

During FY21, UIC-DSCC will continue to participate in the Big 5 CYSHCN State Collaborative on population-based approaches to serving CYSHCN and their families through the Core and Home Care Programs.

*Community-Based Organizations (Priority #7)*

**During FY21, UIC-DSCC will utilize the following strategies and activities to address Priority #7 - Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special health care needs:**

A. **Partner with sister agencies, community organizations, and provider practices to address**
systemic issues and challenges impacting CYSHCN and develop a report with recommendations.

During FY21, UIC-DSCC will identify and partner with sister agencies, community organizations, and/or provider practices to address at least 3 systemic topics impacting CYSHCN. Based on previous data gathering, topics under consideration will include Integrated Health Homes, respite availability, alternate caregivers for medically complex children, single point of entry for pediatric waivers, medical neglect partnership with DCFS, access to dental care for CYSHCN, transportation issues, TPN lab draws for kids enrolled in waiver.

B. Expand UIC-DSCC Family Advisory Council to include participation from families of CYSHCN who may not be enrolled in one of DSCC’s care coordination programs.

During FY21, UIC-DSCC will continue to partner with communities, consumers and families by convening and facilitating the Family Advisory Council. UIC-DSCC will also make a concerted effort to recruit and include the participation of families of CYSHCN who may not be enrolled in UIC-DSCC’s care coordination programs. This effort will ensure that UIC-DSCC has input from stakeholders outside of the UIC-DSCC’s normal network of partners and bring in additional perspectives needed to serve families across Illinois.

C. Collaborate with the state’s Medicaid agency to develop strategies to improve home nursing coverage and address financial challenges for medically fragile children and youth in Illinois.

In July 2019 the IL Medicaid Program notified UIC-DSCC that children with special health care needs would be moving into mandatory managed care. UIC-DSCC was asked to partner with the 6 Medicaid Managed Care Plans (MCOs) to continue serving individuals who were already enrolled in the UIC-DSCC Core Program. UIC-DSCC developed a new care coordination program, Connect Care, in order to continue serving this population. The development of relationships with MCOs has allowed UIC-DSCC to make additional relationships with additional systems serving CYSHCN.

UIC-DSCC will continue to partner with the MCOs to continue serving its constituents. Additionally, UIC-DSCC provided direct “gap-filling” financial assistance to enrolled program participants who met financial eligibility and presented a need.

UIC-DSCC also plans to partner with the state’s Medicaid agency to hold listening sessions pertaining to caregiver and nursing needs for medically-fragile children and youth in IL to help in the development of strategies to improve home nursing coverage for those who need it.

D. Continue to support the Advance Practice Nurse (APN) fellowship for developmental pediatrics.

CYSHCN stakeholder interviews indicated a need for additional partnerships across communities pertaining to services needed by CYSHCN. This need was reinforced in the expert panel reviews where recommendations included the need for improved partnerships with other entities serving CYSHCN including alternative providers such as Advanced Practice Nurses. Accordingly, UIC-DSCC will continue to support the Advance Practice Nurse (APN) fellowship for developmental pediatrics. This unique fellowship training is intended to address issues pertaining to access of developmental pediatricians in Illinois. UIC-DSCC will serve as a clinical partner to Almost Home Kids.

E. Promote educational resources available through DSCC’s online library to parents and caregivers of CYSHCN.
During FY21, UIC-DSCC will maintain its online Transition Resource Directory which provides important transition resources including “Transition Milestones,” “Transition Skills, Tips, and Tools,” and the “Transition Toolkit.” It will also continue to post information about transition activities and resources on the website and Facebook page.

F. Collaborate with Illinois Chapter of American Academy of Pediatrics (ICAAP) and other provider groups to improve education, awareness, and usage of medical home best practices in Illinois.

During FY21, UIC-DSCC staff will continue to participate in a variety of state-wide councils and advisory committees pertaining to CYSHCN including Illinois Chapter of the American Academy of Pediatrics (ICAAP) Section Committee on Chronic Illness & Disability, Children’s Justice Task Force, advisory committee for Integrated Health Homes along with HFS, Integrated Care for Kids Partnership Council at Lurie Children’s Hospital, Emergency Medical Services for Children, The Collaborative for Children’s Healthy Policy, Transition Planning Councils, and IL Interagency Council on Early Intervention to help improve education, and awareness of issues concerning CYSHCN and their families, including usage of medical home best practices.

G. Develop informational sheets with facts on impact of social determinants on the health of CYSHCN to be shared with others (e.g., policymakers) and available online.

During FY21, UIC-DSCC will increase awareness on the impact of social determinants of health on CYSHCN across Illinois by developing and disseminating material for various audiences and across multiple modes of communication.
Cross-Cutting/Systems Building - Application Year

Illinois’ priorities for the Cross-Cutting Domains are:

- Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders. (Priority #8)
- Support an intergenerational and life course approach to oral health promotion and prevention. (Priority #9)
- Strengthen capacity and systems for data collection, linkage, analysis, and dissemination (Priority #10)

Mental Health & Substance Use (Priority #8)

During FY21, Illinois Title V will utilize the following strategies to address Priority #8 - Strengthen workforce capacity and infrastructure to screen for, assess and treat mental health conditions and substance use disorders:

A. Partner with the Illinois Children’s Mental Health Partnership to develop and implement a model for children’s mental health consultations for local health departments and other public and private providers in the public health and healthcare delivery system.

During FY21, IL Title V will continue to support the IECMHC public health pilot program which provides 10-12 hours a month of reflective consultation by an infant/early childhood mental health consultant to the selected local departments of public health pilot sites (Stephenson County, Winnebago County, Southern Seven, and East St. Louis) as well as monthly professional development and reflective supervision to promote fidelity to the IECMHC model. The consultation services provided to each site will increase the capacity of each pilot site to prevent, identify, and reduce the impact of mental health concerns among infants, young children, and their families as well as help facilitate connections made to appropriate systems and resources to assist with the needs identified by the public health staff (through the help of the consultants). This directly ties to Title V priority #3 (the consultant will help facilitate integration of and access to early childhood services and systems), #4 (consultants work with public health staff and families to help build the capacity of families to connect to the health and human services they require), and #8 (by providing consultation on infant and early childhood mental health, public staff will increase capacity to access and integrate mental health services).

B. Partner with the Illinois Department of Corrections and Logan Women’s Prison on health promotion activities for incarcerated women focused on substance use recovery and trauma health education.

This is the same as strategy 1-B. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.

C. Partner with UIC Center for Research on Women and Gender to implement a program at two clinic sites to expand the capacity of health care providers in the state of Illinois to screen, assess, refer and treat pregnant and postpartum women for depression and related behavioral health disorders. (Same as strategy 1-E)

This is the same as strategy 1-E. Information about this activity is available in the narrative for the
Women’s and Maternal Health Domain.

D. Convene and facilitate state Maternal Mortality Review Committees (MMRC and MMRC-V) to review pregnancy-associated deaths and develop recommendations to improve quality of maternal care as well as reduce disparities and address social determinants of health. *(Same as strategy 2-A)*

This is the same as strategy 2-A. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.

E. Support the Perinatal Depression Program which provides 24-hour telephone consultation for crisis intervention for women suffering from perinatal depression.

This is the same as strategy 2-J. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.

F. Support the Illinois Perinatal Quality Collaborative (ILPQC) as it seeks to implement obstetric and neonatal quality improvement projects initiatives in birthing hospitals *(Same as strategy 2-I).*

This is the same as strategy 2-I. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.

G. Collaborate with other state and national initiatives to address opioids and substance use to ensure a focus on women of reproductive age, including participation in the ASTHO Opioid Use Disorder, Maternal Outcomes, Neonatal Abstinence Syndrome Initiative (OMNI) Learning Collaborative.

During FY21, IDPH will continue to serve as a member of the Illinois team invited to participate in the ASTHO Opioid Use Disorder, Maternal Outcomes, Neonatal Abstinence Syndrome Initiative (OMNI) Learning Collaborative. The Illinois team is comprised of representatives from IDPH, HFS (Medicaid), DHS, DCSF (child welfare), and the Illinois Perinatal Quality Collaborative. The team's OMNI project focuses on Illinois having a “recovery-oriented system of care that enables women planning pregnancy, and pregnant and postpartum women to receive medication-assisted treatment (MAT) and needed support services to have healthy pregnancies and deliveries and be supported in the postpartum period for the development of healthy families.” The team identified several barriers to MAT for women with substance use disorder (SUD), including lack of providers, lack of provider awareness/training, lack of care coordination and fragmented system, lack of identification/screening, reimbursement issues, prenatal care providers lacking experience and process to link women to MAT providers, stigma, and the social determinants of health (transportation, housing, child care). The goals of the project are:

- Expand access to MAT for pregnant women with SUD by increasing the number of providers trained to screen/diagnose SUD, administer MAT, and counsel patients;
- Develop a cross-system communication plan for the health care, Medicaid, substance use prevention/treatment, and child welfare systems that reduces stigma around substance use disorder and creates standardized systems of support for pregnant women with SUD and their infants; and
- Develop cross-system training for providers delivering prenatal care, labor/delivery staff in hospitals, and the child welfare system to establish standardized protocols and practices which
would assure optimal care to infants born with Neonatal Abstinence Syndrome (NAS).

OWHFS and IL Title V will continue to work to increase education and support of health care providers and patients around the use of LARC. This includes working with the Illinois Department of Corrections to incorporate family planning into the two women’s prisons to offer family planning services to women prior to release, collaborating to expand the efforts of ILPQC’s immediate postpartum LARC initiative and integrating the Title X Family Planning Program with school-based health centers.

H. Identify gaps in mental health programs and resources for Illinois children; develop partnerships with and within organizations focused on improving mental health among children and adolescents; and support the implementation of mental wellness programs that facilitate system level improvements as well as address social determinants of health. (Same as strategy 4-D)

This is the same as strategy 4-D. Information about this activity is available in the narrative for the Child Health Domain.

I. Participate on and collaborate with statewide Adolescent Suicide Ad Hoc Committee to develop strategic plan to reduce suicide ideation and behavior among youth in Illinois (Same as strategy 5-C).

This is the same as strategy 5-C. Information about this activity is available in the narrative for the Adolescent Health Domain.

J. Convene and partner with key stakeholders to identify gaps in mental health and substance abuse services for women that include difficulties encountered in balancing multiple roles, self-care and parenting after childbirth; and leverage expertise to develop recommendations for system level improvements for Title V consideration and implementation. (Same as strategy 2-G).

This is the same as strategy 2-G. Information about this activity is available in the narrative for the Women’s and Maternal Health Domain.

**Oral Health (Priority #9)**

During 2021, Illinois Title V will utilize the following strategies to address Priority #9 - Support an intergenerational and life course approach to oral health promotion and prevention:

A. Partner with IDPH Division of Oral Health (DOH) to expand oral health outreach to the most at-risk maternal populations by engaging Woman, Infant and Children (WIC) programs within local health departments.

During FY21, DOH will work directly with pregnant women through the Woman, Infant and Children (WIC) programs within local health departments providing assistance for the most at risk maternal population. This initiative will serve to bring a greater awareness of the oral systemic link between low birth weight and pre-term labor. By working directly with Woman, Infant and Children (WIC) programs within local health departments, DOH will be able to provide assistance for the most at risk maternal population. In addition, DOH will continue to reach out to Health Departments to provide technical assistance and guidance for oral health programs. These programs include the fluoride varnish trainings medical dental integration and referrals to care programs.
B. Partner with the DOH to support and assist school personnel and families across Illinois to access: oral health education, dental sealants, fluoride varnish, Illinois All Kids (Medicaid) enrollment, dental home referrals and comply with Illinois’ mandatory school dental examinations for children in kindergarten, second, sixth and ninth grades.

During FY21, DOH will continue to partner with Illinois Title V to provide continued funding to local health departments for dental sealants for uninsured or underinsured children. In addition, DOH will continue to inform, educate, and empower others about oral health issues through such vehicles as providing oral health presentations for daycares and schools for children of all ages, and presentations and exhibiting at school nurses’ meetings and oral health screenings at local health fairs will continue to be a priority.

C. Collaborate with DOH to design and implement the first Basic Screening Survey (BSS) for Pregnant Women in Illinois that will assess the burden of oral diseases and barriers to access care.

In FY21, DOH will use established methodology to implement the Basic Screening Survey (BSS) for Pregnant Women with technical guidance from IL Title V epidemiologists, as needed. Results will be compiled in a comprehensive and detailed report of the findings for dissemination to stakeholders.

D. Participate in “Implementation of Quality Indicators to Improve the Oral Health of the Maternal and Child Health Population” Pilot Project with DOH to pilot a series of measures to inform the creation of a national set of indicators.

During FY21, IDPH Division of Oral Health will continue to work with HFS to promote and understand the reach of preventive and periodontal care received by women during pregnancy. DOH is developing a framework for an Illinois Oral Health Surveillance System which includes identifying and developing oral health data sets/measures for annual surveillance that inform partners state-wide, data extraction, testing and modifying (if needed) data transfer, and formatting content. The first wave of data to be presented include non-traumatic use of the emergency department. Data will be mapped by county, sex, age grouping including children (18 years old and younger). This set of data will help inform community partners to better understand needs and create plans to meet these needs. IL Title V epidemiologists and staff will continue to support this effort.

E. Participate in Partnership for Integrating Oral Health Care into Primary Care project with DOH and a local health department to integrate the interprofessional oral health core clinical competencies into primary care practice, particularly for pregnant women and adolescents.

During FY21, IL Title V will continue to partner with DOH and the Champaign-Urbana Public Health District to participate in the Partnership for Integrating Oral Health Care into Primary Care Project sponsored by Center for Oral Health Systems Integration and Improvement (COHSII) consortium that began in FY19. Primary care providers at the local health department are being trained to use the Smiles for Life curriculum and then subsequently provide oral health risk assessments, oral exams, and fluoride varnish to adolescents and pregnant women recruited through their Women, Infants and Children (WIC) program. This pilot will be continued in FY21 through financial support of COHSII and the IL Title V. The pilot will continue to document the need for services in primary care settings.

In addition, IL Title V would like to highlight the upcoming Oral Health During Pregnancy and Early Childhood in Illinois resource manual which will be finalized and published early FY21. IL Title V will work with DOH to educate, promote, and disseminate the completed manual to partners.
Another notable activity for FY21 is Title V’s continued support for the development of a new statewide oral health plan. The last statewide plan was updated in FY17. DOH has started convening stakeholders to participate on the Advisory and Steering Committee for the development of the Illinois’ Oral Health Plan IV. The goal is to reassess the oral health landscape, consider challenges, opportunities, and update strategies that aim to improve oral health status, and decrease prevalence of oral diseases.

*MCH Epidemiology Capacity and Data Systems (Priority #10)*

For the new Illinois MCH Action Plan for the years 2021-2025, the strategies have been condensed to better categorize and classify the work of the Title V epidemiology team.

**During FY21, Illinois Title V will utilize the following strategies to address Priority #10 - Strengthen capacity and systems for data collection, linkage, analysis, and dissemination:**

A. **Enhance staff capacity for data management, analysis and translation through training and workforce development**

*Training Opportunities*

Training opportunities will continue to be offered to Title V staff members as they are available and feasible. For example, new Title V epidemiologists may apply to participate in the weeklong MCH epidemiology training sponsored by MCHB in June 2021. Other opportunities, such as pre-conference trainings and the CDC/Harvard Program Evaluation practicum, will also be explored for their relevance to staff training needs. As the need arises, Title V epidemiology staff may provide data-focused trainings to other staff members, such as providing overviews of program evaluation, needs assessment processes, data interpretation, or other relevant topics.

*Workforce Development for Interns, Fellows, and Early Career Professionals*

Illinois Title V will continue to be dedicated to developing young professionals through epidemiology internships and fellowships. During FY21, we will host graduate epidemiology students for internships through agreements with local universities such as the UIC CoE-MCH and DePaul University.

Illinois will host a CSTE applied epidemiology fellow from August 2020 through August 2022. The CDC MCH Epidemiology field assignee will serve as the primary mentor for this fellow.

Illinois applied to be a host site for the CDC Public Health Associate Program (PHAP), which is a 2-year training program for early public health professionals. The proposed position would focus on emergency preparedness planning for MCH populations – a topic area that Illinois Title V would like to more actively engage and develop for the state. The Title V Director would serve as the supervisor for this position. If selected as a host site, OWHFS will host the Public Health Associate from October 2020 – September 2022.

B. **Improve data infrastructure and systems, including initiatives to improve accuracy, timeliness, and quality of data**

*Data Linkage*
Linkage of data systems has long been identified as a need to improve MCH surveillance, and Illinois Title V will continue to prioritize linkage of MCH data sources. Epidemiology staff will continue to implement probabilistic matching to improve the linkage rate and quality for the infant birth and death certificates. Additionally, while the process of linking hospitalization and birth certificate data was begun during FY18 by the CSTE Applied Epidemiology Fellow, this project was not completed prior to the end of her fellowship. Multiple demands upon staff time have made continued progress on this linkage slow. During FY19-FY20, a PhD level epidemiology student intern has assisted IDPH with the continued linkage of hospital discharge and birth certificate data. The hope is that the permanent Title V epidemiology staff will be able to take over this function in FY21.

Maintenance of Data Systems

During FY21, Title V will continue to maintain the ePeriNet data system as the primary reporting mechanism for quality and outcome data from the perinatal hospitals. As needed, updates and improvements to ePeriNet will be made to ensure that the data are useful and of high quality. For example, the addition of a COVID-19 module for maternal and infant outcomes is planned for late 2020 and will likely extend into 2021.

Illinois will maintain use of the CDC-hosted MMRIA system during FY21 to record information about all pregnancy-associated deaths and to share this information with the CDC.

C. Analyze data, translate findings, and disseminate epidemiologic evidence to support MCH decision-making

Generating and disseminating epidemiologic evidence remains at the heart of the state Title V priority on data. Data products and reports will continue to be developed for a variety of audiences based on emerging topics of interest. These products may include fact sheets, infographics, data briefs, or longer data reports. Some specific data products that are anticipated for FY21 include:

- An annual update to the state report on maternal morbidity and mortality
- Data brief on mental health and substance use hospitalizations for women of reproductive age
- Data report on the state’s first in-depth analysis of fetal deaths
- Data report comparing maternal morbidity data across multiple data sources

Conference attendance and presentations will continue to be a priority as a means for disseminating the work of the Illinois Title V epidemiology team. Staff members will prepare scientific abstracts to submit to conferences during FY21, such as the annual conferences of the Association of Maternal and Child Health Programs (AMCHP), CityMatCH, and the Council of State and Territorial Epidemiologists.

As appropriate, Title V staff will also contribute to the development of manuscripts that will be submitted to peer-reviewed journals. This may include leading the development of papers based on studies involving Title V data or programs, as well as contributing as a co-author on papers led by external partner organizations or by trainees/interns working with Title V.

D. Forge partnerships that will increase the availability, analysis, and dissemination of relevant and timely MCH data

Partnerships to Increase Epidemiology Capacity of IL Title V
Illinois has hosted a CDC MCH epidemiology field assignee since 2014 and plans to continue this valuable partnership during FY21.

IDPH began hosting a CDC COVID-19 epidemiology field assignee in July 2020, and this position will continue through June 2021. Sonal Goyal, PharmD, MPH, is the COVID-19 epidemiology assignee, and her work with Illinois will focus on supporting maternal and child health related COVID-19 surveillance. Her state supervisor is the CDC MCH epidemiology field assignee.

The interagency agreement with the UIC School of Public Health, CoE-MCH is in the process of being renewed. The proposed new agreement would run through June 2022, thus continuing this vital partnership throughout 2021. This will enable Illinois Title V to continue to benefit from the epidemiologic technical assistance provided by UIC faculty, staff, and students. Projects may include detailed data analyses, program evaluations, and/or creation of fact sheets or other data products.

During FY21, the UIC-DSCC and the UIC CoE-MCH will continue to collaborate on data-related projects that inform services for CSHCN in Illinois. Specific projects will be developed in response to the future needs of the program.

**Partnerships to Improve Access and Quality of MCH Data**

During FY21, the Title V epidemiology team will continue to provide technical assistance to various partners on data projects. This will include collaboration with the Illinois Perinatal Quality Collaborative, state advisory committees (e.g., Perinatal Advisory Committee, Statewide Quality Council), and various other state agencies. Additionally, Title V will maintain and build upon relationships with other internal IDPH data staff (e.g., PRAMS, BRFSS, Vital Records, Hospital Discharge data) through collaborative data sharing agreements.

Title V and PRAMS will continue to actively partner to ensure high-quality data collection during FY21. These activities will include: continuing to fund the incentives for survey respondents, supporting the implementation and analysis of a new PRAMS COVID-19 supplement, and collaborating on phase 9 survey development. Title V will ensure that questions representing Title V priorities, such as the social determinants of health, are included in consideration for new questions.

Title V will also continue the completion of the SDOH form for every maternal death case that will be reviewed by the MMRC/MMRC-V. The state MMRCs will also routinely use a community vital signs dashboard (developed by Emory University) as part of a pilot project to help state MMRCs apply a health equity framework to maternal mortality reviews.

**End Public Comment Document Here**
III.F. Public Input
Illinois’ draft of the Title V Maternal and Child Health Services Block Grant FY2021 Application/2019 Annual Report was shared with IDPH and IL Title V Advisory Groups and stakeholders for feedback. In addition, the Application/Annual Report was posted on the IDPH website for public comment. This feedback/public comment period occurred from August XXX, 2020 through September XXX, 2020. All stakeholder and public comments were reviewed and, when possible, were incorporated into the final version of the FY2021 Application/FY2019 Annual Report to be submitted September 15, 2020.

The following organizations provided feedback:
  o  Information will be provided after the feedback/public comment period

The UIC-DSCC Family Advisory Council reviewed the portions of the application pertaining to services for CYSHCN on (Date).

As part of the FY2020 Title V Needs Assessment, the IL Title V engaged the public and stakeholders in multiple ways. ...... by deploying a survey over the Department’s social media account.

III.G. Technical Assistance
Due to the COVID-19 Pandemic, IL Title V had to postpone several technical assistance workshops it had scheduled. The Program would like to reschedule those workshops in the near future. Technical assistance continues to be needed in the following areas.

Program Planning and Evaluation
IL Title V staff would like additional training in program planning and evaluation. All staff would benefit from a refresher in program planning, monitoring and evaluation especially as it pertains to the current grant portfolio.

Family and Consumer Engagement
The IL Title V seeks to improve upon family and consumer engagement for the general MCH population in a way that is organic and routine. Unfortunately, staff time remains the primary barrier to strategically planning activities in this area.