Title V Maternal and Child Health Services Block Grant:
2020 Needs and Capacity Assessment

Bureau of Family Health

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DEPARTMENT OF HEALTH

Abbreviations

95% CI	95% Confidence Interval
ACEs	Adverse childhood experiences
BFH	Bureau of Family Health
BHPRR	Bureau of Health Promotion and Risk Reduction
BRFSS	Behavioral Risk Factor Surveillance System
CAHS	(Division of) Child and Adult Health Services
CDC	Centers for Disease Control and Prevention
CDC WONDER	CDC Wide-ranging Online Data for Epidemiologic Research
CDR	Child Death Review
CHIP	Children’s Health Insurance Program
CHOP	Children’s Hospital of Philadelphia
CMHD	County/municipal health department
CSDO	(Division of) Community Systems Development and Operations
CSHCN	Children with special health care needs
DBO	Division of Bureau Operations
DCED	(Pennsylvania) Department of Community and Economic Development
DDAP	(Pennsylvania) Department of Drug and Alcohol Programs
DOH	(Pennsylvania) Department of Health
DHS	(Pennsylvania) Department of Human Services
EDDIE	Enterprise Data Dissemination Informatics Exchange
ESM	Evidence-based Strategy Measure
FQHC	Federally Qualified Health Center
HCUP	Health Care Cost and Utilization Project
HP2020	Healthy People 2020
HPV	Human papillomavirus
HRSA	U.S. Department of Health and Human Services Health Resources and Services Administration
ICC	Interconception care
ICD	International Statistical Classification of Diseases and Related Health Problems (ICD-9, ninth revision; ICD-10, tenth revision)
IUD	Intrauterine device
JHBSPH	Johns Hopkins Bloomberg School of Public Health
LEND	Leadership Education in Neurodevelopmental Disabilities Program
LGBTQ	Lesbian, gay, bisexual, transgender and questioning
MATP	Medical Assistance Transportation Program
MCHB	Maternal and Child Health Bureau
MCHSBG	Maternal and Child Health Services Block Grant
MCO	Managed care organization
MIECHV	Maternal, Infant, and Early Childhood Home Visiting
MMRC	Maternal Mortality Review Committee
NAS	Neonatal abstinence syndrome
NICU	Neonatal intensive care unit
NCFRP-CRS	National Child Fatality Review and Prevention - Case Reporting System
NIS	National Immunization Survey
NOM	National Outcome Measure

NPM	National Performance Measure
NSCH	National Survey of Children’s Health
NSFP	Newborn screening follow-up program
NSG	(Division of) Newborn Screening and Genetics
OCDEL	Office of Child Development and Early Learning
OHE	Office of Health Equity
OHMSAS	Office of Mental Health and Substance Abuse Services
OMAP	Office of Medical Assistance Programs
DOH	Pennsylvania Department of Health
PA PRAMS	Pennsylvania Pregnancy Risk Assessment Monitoring System
PaTTAN	Pennsylvania Training and Technical Assistance Network
PAYS	Pennsylvania Youth Survey
PEAL	Parent Education, Advocacy, and Leadership Center
PHC4	Pennsylvania Health Care Cost Containment Council
PIHET	Pennsylvania Interagency Health Equity Team
PMSS	Pregnancy Mortality Surveillance System
PRAMS	Pregnancy Risk Assessment Monitoring System
SFY	State fiscal year
SHIP	State Health Improvement Plan
SPM	State Performance Measure
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TBI	Traumatic brain injury
USDA	U.S. Department of Agriculture
WIC	(Pennsylvania Special Supplemental Nutrition Program for) Women, Infants and Children
YRBS	Youth Risk Behavior Survey
YRBSS	Youth Risk Behavior Surveillance System

Executive Summary

Background: Title V Five-Year Needs and Capacity Assessment

Every five years, Title V legislation requires that Pennsylvania's Title V Maternal and Child Health Services Block Grant (MCHSBG) team, housed in the Bureau of Family Health (BFH), conduct a Five-Year Needs and Capacity Assessment. The objective of the assessment is to comprehensively evaluate the health status of women, infants, children, adolescents, and children and youth with special health care needs in Pennsylvania in order to identify the priority health needs that will guide the work funded by Title V dollars. During this assessment, the BFH also evaluates its capacity to serve maternal and child health (MCH) populations in Pennsylvania.

Preparation and Planning

Initial preparation for the assessment included review of the guidance provided by the U.S. Department of Health and Human Services Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), development of the assessment timeline and work plan, and identification of the assessment's guiding principle. For the 2020 Title V Five-Year Needs and Capacity Assessment, the BFH's guiding principle was health equity. In addition, the BFH assembled an internal Needs Assessment Steering Committee that would oversee and direct the assessment.

Characterization of Maternal and Child Health Population Health Status

In order to assess the health status of MCH populations, state and national datasets were analyzed, and statistics on a series of key health indicators were summarized for each Title V population domain. Additionally, qualitative data on the health needs of families and communities were collected from stakeholders via focus groups and a web survey focused on social determinants of health. Results from the quantitative and qualitative data analyses were summarized into a series of data briefs in order to provide stakeholders with interim results of the data analysis phase of the needs assessment. The data briefs, included in the Appendix, provide an executive summary of the results of the data analysis.

Prioritization and Identification of Needs

In preparation for selecting priorities for the next five-year cycle of the Title V MCHSBG, the BFH worked with a team from the Johns Hopkins Bloomberg School of Public Health (JHBSPH) Center for Excellence in Maternal and Child Health Education, Science and Practice to develop a framework for prioritization. A component part of this framework was the selection of a set of values. Literature on needs assessment indicates that needs analyses are improved by an explicit definition of what constitutes a "need," with consensus on the values that are most important when selecting among competing priorities. The initial list of values identified was reviewed by the Department of Health's Office of Policy and the department's leadership, including Secretary of Health Dr. Rachel Levine, to ensure that the values were consistent with the agency's mission before the BFH adopted them as part of their framework.

In order to develop the initial list of priorities, the BFH considered all of the National Outcome Measures (NOMs) and National Performance Measures (NPMs) put forward for Title V by HRSA, as well as the corresponding data that had been analyzed as part of the characterization of MCH population health status. NOMs and NPMs were then scored based on the list of pre-identified values and the BFH's data briefs, which summarized the state and national health data that had been analyzed and data from the focus groups and web survey related to social determinants of health in Pa. The preliminary list of 21 priorities was also reviewed by the Department of Health’s Office of Policy and Secretary Levine. It was determined that all the potential priorities could be feasibly addressed by the agency and that many of them were in direct alignment with Secretary Levine’s initiatives related to maternal and child health in Pennsylvania. That list of 21 priorities was subsequently presented at five regional meetings held between September and October 2019, at which Title V stakeholders and families were invited to rank priorities for each population domain. Additionally, stakeholders had an opportunity to consider and rank the priorities at a health equity summit, at an adolescent health event and through a web survey that the BFH distributed to stakeholders who were unable to attend one of the in-person events.

Capacity Assessment

Additionally, the BFH completed several activities that would allow them to assess their capacity to carry out the mission of Title V and to direct work related to the newly proposed priorities. In addition to evaluating the existing infrastructure and capacity of the Department of Health (DOH) and the BFH, a component of the workforce capacity assessment was surveying Title V staff on their competencies related to maternal and child health, as well as areas where more training is desired. As a result of these surveys, the BFH determined that there is a need for and interest in continued training around evidence-based decision making, health equity, the social determinants of health and models of engaging community members and stakeholders in Title V work.

The BFH also held an in-person meeting with the DOH and other agency partners in November 2019 at which the BFH sought feedback on the health needs that stakeholders identified as being the highest priorities and discussed organizational capacity. Staff members from the BFH, other bureaus and offices within the DOH, and the Department of Human Services (DHS) broke out into working groups for focused discussion. Participants offered input on the proposed Title V priorities considering organizational capacity and health equity and had an opportunity to rank the remaining priorities under consideration.

Findings: Final Priorities for Title V MCHSBG Cycle 2021-2025

Rankings and comments from the five regional prioritization meetings, the additional in-person events, web survey and the agency meeting were subsequently analyzed and summarized.

Using that information, the initial list of priorities was narrowed to the top six included below. The seventh priority was developed in response to feedback from stakeholders engaged throughout the process who indicated that the BFH’s commitment to advancing health equity through Title V work should be explicit. These seven priorities were then approved by the BFH’s Needs and Capacity Assessment Steering Committee and the DOH’s leadership team, including Secretary Levine.

1. Reduce or improve maternal morbidity and mortality, especially where there is inequity.
2. Reduce rates of infant mortality (all causes), especially where there is inequity.
3. Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs.
4. Improve the percent of children and youth with special health care needs who receive care in a well-functioning system.
5. Reduce rates of child mortality and injury, especially where there is inequity.
6. Strengthen Title V staff’s capacity for data-driven and evidence-based decision making and program development.

7. Support and effect change at the organizational and system level by supporting and promoting policies, programs and actions that advance health equity, address the social, environmental and economic determinants of health, and deconstruct institutionalized systems of oppression.

Development of State Action Plan

The seven priorities listed above will guide the BFH as it develops a five-year action plan and identifies strategies that can be implemented to advance health equity and improve health outcomes among maternal and child health populations in Pennsylvania over the next Title V MCHSBG five-year funding cycle. Component parts of the action planning phase include selection of NPMs and NOMs, development of State Performance Measures (SPMs) as needed, development of Evidence-based Strategy Measures (ESMs) and development of performance and process objectives that will be used to evaluate progress made over the course of the five-year period.

Overview of the Requirements of the Title V Five-Year Needs and Capacity Assessment

The Title V Maternal and Child Health Services Block Grant (MCHSBG) legislation (Section 505(a)(1)) requires that each state complete a comprehensive, statewide needs and capacity assessment every five years. The needs and capacity assessment provides each state with the opportunity to measure the impact and progress made through Title V work over the previous five years and to identify gaps in the provision of appropriate and coordinated services for maternal and child health populations. According to the Health Resources and Services Administration (HRSA) guidance, objectives of the assessment include "identify[ing] the need for preventive and primary care services for pregnant women, mothers, infants up to age one, children [age 1 through 21], and children with special health care needs," improving maternal and child health outcomes, and strengthening state, local, and community partnerships (U.S. DHHS, 2015, p. 17). Required components of the needs and capacity assessment include engagement of stakeholders, assessment of needs of the maternal and child health populations, assessment of capacity and selection of the seven to 10 priorities on which the state will focus in the subsequent five-year Title V funding cycle.

The primary outcome of the Title V Five-Year Needs and Capacity Assessment is a set of priority needs (between seven and 10) that are unique to the state and developed based on the findings of the assessment. The identified priorities are instrumental in guiding the creation of a five-year action plan, the selection of performance measures, development of performance objectives and strategies and the subsequent allocation of Title V funds and resources.

Methods

Plan and Timeline Development

In November 2018, a plan for the Title V Five-Year Needs and Capacity Assessment was developed by the Bureau of Family Health's (BFH) needs assessment coordinator, in accordance with HRSA's guidance. The plan provided details on the methods and anticipated outcomes of the needs and capacity assessment, a preliminary description of the prioritization process, and a timeline of the steps required to complete the assessment. The approved plan and final timeline are included in the Appendix (Supplement A).

Part of the planning phase was identification of a guiding principle for the assessment. Based on the feedback from the 2015 Title V Five-Year Needs and Capacity Assessment, the guiding principle of the 2020 needs and capacity assessment was health equity. Health equity is achieved when all people have the opportunity to attain their full health and wellness potential. As such, in addition to analyzing data and gathering information from stakeholders to characterize the health issues facing all MCH populations in Pennsylvania (Pa.), the assessment also aimed to identify specific population groups that are disproportionately affected by adverse health outcomes including illness, disease, and mortality and to evaluate underlying, influential determinants of health such as social, economic, and environmental factors.

An overview of the plan for the needs and capacity assessment as well as the timeline were summarized into a one-page document that was made available on the Title V website and shared with stakeholders (Appendix, Supplement B). An essential, ongoing component of the BFH's Title V Five-

Year Needs and Capacity Assessment was stakeholder involvement and engagement. Title V staff from the BFH presented on the Title V Five-Year Needs and Capacity Assessment at advisory board meetings and at meetings with Title V grantees and partners throughout the planning and data analysis phases of the assessment. By highlighting opportunities for both provider and consumer engagement during these presentations, the bureau hoped to raise awareness of the assessment and encourage robust participation in web surveys, focus groups and the prioritization, all of which would be completed in collaboration with stakeholders. Presentations were made at the following meetings:

- County/Municipal Health Department Meeting, April 10, 2019;
- Perinatal Partnership Meeting, April 11, 2019;
- Specialty Care Symposium, April 30, 2019;
- Traumatic Brain Injury Advisory Board Meeting, May 10, 2019;
- Leadership Education in Neurodevelopmental Disabilities Community Advisory Board Meeting, May 13, 2019;
- Personal Responsibility Education Program Grantee Meeting, May 22 and 23, 2019;
- State Transition Leadership Team Meeting, June 6, 2019; and
- State Interagency Coordinating Council Meeting, June 13, 2019.

Convening the Needs Assessment Steering Committee

Once the plan was final, a Needs Assessment Steering Committee was assembled in order to assist with implementation. The steering committee was a planning and advisory committee, providing guidance and feedback on the proposed framework of the needs and capacity assessment. Given that the needs assessment required collaboration across all divisions of the BFH, the goals of the Steering Committee were to delegate responsibilities across sections based on expertise and skills of staff and to foster teamwork and coordination throughout the project period. The steering committee also provided direction throughout the assessment by identifying stakeholders, reviewing methods of primary data collection and engaging in the identification and prioritization of MCH needs. The committee was composed of the directors of the Division of Community Systems Development and Outreach, the Division of Child and Adult Health Services, the Division of Newborn Screening and Genetics, the Division of Bureau Operations, the Director of the BFH, staff from the Office of Health Equity, program staff, the needs assessment coordinator and the maternal and child health epidemiologist. The following staff participated as members of the Needs Assessment Steering Committee over the course of the assessment: Tara Trego, Erin McCarty, Kelly Holland, Cindy Dundas, Naomi Zeiset, Stacey Gustin, Kim Buffington, Nhiem Luong, Sara Thuma, Angelo Santore, Aerielle Waters and Caryn Decker.

Statistical Analysis of State and National Data

The next step of the needs assessment was to characterize the health and wellness of MCH populations in Pa. by analyzing available state and national health data. A list of indicators was developed for each population domain to guide the analyses. All of HRSA’s NPMs and NOMs, as well as many of the health indicators identified by the U.S. Department of Health and Human Services’ Healthy People 2020 (HP2020), were included for consideration. The NPMs and NOMs served as a useful framework for characterizing the health of MCH populations, as they were developed by the federal government to monitor and measure the progress and impact of the Title V Programs nationally. Similarly, Healthy People 2020 is a list of indicators and benchmarks that were developed to characterize and improve the nation’s health and, as such, are well-suited to the goals of the assessment. Indicators that have been phased out or archived were excluded, and indicators that seemed redundant or that captured similar, if not the same, information about the populations were merged. After settling on a list of key indicators, the indicators were categorized as indicators of wellness, health risk factors, morbidity or mortality.

Staff members from the BFH were assigned a set of indicators and asked to gather data on that indicator from the past five years in order to determine whether health outcomes had improved, declined or remained the same. Overall, staff evaluated data from 11 datasets, not including data that is internal to the BFH or the DOH, for the five Title V populations: women, infants, children, adolescents, and children and youth with special health care needs. Data was also stratified by race/ethnicity, age, socioeconomic status, sex, gender identity and sexual orientation whenever possible. Publicly available data and summary statistics published online were gathered for the following datasets: American Community Survey (ACS, 2015-2017), CDC Wonder Detailed Mortality and Linked Infant Death/Birth Datasets (2012-2016), National Center for Fatality Review and Prevention – National Reporting System (2011-2015), National Immunization Survey (2014-2018), the National Survey for Children’s Health (NSCH, 2016-2017), Pennsylvania Youth Survey (PAYS, 2013, 2015 and 2017), Pennsylvania Health Care Cost Containment Council (PHC4, 2008-2017), and the Youth Risk Behavior Survey (YRBS, 2009, 2015, 2017). Data from Pa. birth certificates and death certificates were summarized from the Pa. Department of Health’s online data platform, EDDIE for 2012-2017. Data files were procured for PRAMS Phase 7 data (2012-2015), PRAMS aggregate site data from 34 PRAMS sites (2012-2015), and BRFSS (2011-2017) and were analyzed for relevant health indicators using Stata (version 13.0; Stata Corp., College Station, TX). The data sources, indicators evaluated, as well as relevant limitations are described in the Appendix (Supplement C).

Given that the data presented in this report were pulled from multiple datasets, data presentation and the variables available for stratification vary by dataset. Whenever possible, a 95% confidence interval reflecting the amount of random error in the sample is presented for each point estimate. The 95% confidence intervals should be referenced to inform interpretation of the data presented. Given that most of the data presented were accessed using interactive data queries available online, additional comparative analyses were often not feasible, and measures of statistical significance (i.e., p-values) are not presented.

Characterization of Health Status: Maternal and Child Health Populations

Women's and Maternal Health

Population

This section discusses the health status of women and mothers in Pa. This includes women, pregnant women, and women who have recently given birth and are in the postpartum period – the period within 60 days of delivery (U.S. DHHS, 2015, Appendix p. 100). As of 2017, Pa. is home to over 12.8 million people, of whom 51% are women. The median age of women in Pa. is 42.5 years, and 36.5% of women are between the ages of 15 and 44 (U.S. Census Bureau, ACS 5-Year, 2013-2017).

Wellness and Access to Health Care

Well Woman Visit: An annual preventive visit is recommended for all women so that services including screening, counseling and immunizations can be provided. According to BRFSS, the percentage of women in Pa. aged 18 to 45 who reported a well woman visit within the past 12 months increased from 57.9% in 2011 to 61% in 2017. While the percentage of women with a well woman visit has increased over time in Pa., there are differences in the percentage of women who had a preventive medical visit within the past year by race/ethnicity and educational attainment. During 2011 to 2017, women with lower educational attainment were more likely to have had a well woman visit. Approximately 61% of women with a high school education, GED or below had a well woman visit as compared to only 59.5% of women who had a bachelor's degree or above. Similarly, during 2011 to 2017, 71.8% of black/African American women reported a preventive visit within the past year as compared to only 58.1% of white women (CDC, BRFSS, 2011-2017).

Discussion of Pre-conception Health: Discussion of health prior to conception is not only important for pregnancy outcomes but also for the long-term health of women who may or may not have children. As of 2015, 23.5% of PA PRAMS respondents who had a live birth reported having discussed preconception health behaviors with a health care worker prior to pregnancy. This is an improvement from 2014, when only 19.2% of women reported such a discussion, and exceeds the percentage of women reporting a pre-conception health discussion in the PRAMS site aggregate, which was 22.8% in 2015. Pa. is still short of the HP2020 goal of having 27% of women report having discussed preconception health with a provider (ODPHP, 2020). According to PRAMS Phase 7 data (2012-2015), young women (19 years or under) were less likely to have had a preconception health discussion (15.3%) as compared to older women (22.0%), while unmarried women (15.6%) were less likely to have had a preconception health discussion as compared to married women (24.6%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Multivitamin Use: Taking a multivitamin or folic acid containing vitamin prior to pregnancy is associated with improved health outcomes for mother and infant. As of 2015, PA PRAMS data indicated that 49.6% of women reported taking a multivitamin or folic acid containing vitamin prior to pregnancy, an increase from 2014 (43.0%). Pennsylvania also exceeds the HP2020 goal of 33.3% of women reporting multivitamin use prior to pregnancy and the PRAMS site aggregate in 2015, which was 46.2%. PA PRAMS Phase 7 data (2012-2015) suggest that multivitamin use is lowest among women with a household annual income <$15,000/year (24.1%) as compared to women with higher household annual income; approximately 65% of women in households with >$52,000/year reported vitamin usage (ODPHP, 2020). Additionally, young women ≤ 19 years old (23.6%) were less likely to have reported vitamin usage as compared to older women. Vitamin usage increased with incrementally older maternal age, with 46.1% of women aged 20 to 34 reporting taking multivitamins and 56.4% of women aged 35 and older reporting similar usage. There are also differences in multivitamin use by race as multivitamin use prior to pregnancy is lowest among black/African American (32.5%) and Hispanic (32.8%) women as compared to white (50.8%) and Asian (52.2%) women (CDC, PRAMS, 2012-2015; DOH, PA PRAMS 2012-2015).

Healthy Pre-pregnancy Weight: Maintaining a healthy weight prior to pregnancy can reduce the likelihood of weight-related complications during pregnancy. As of 2015, 48.1% of Pa. PRAMS respondents reported having a normal weight (BMI between 18.4 and 24.9) prior to pregnancy, while 47.4% of women reported being overweight or obese prior to pregnancy (PRAMS 2012-2015, Indicator 11). When looking at data from 2012 to 2015, no trend is apparent in PA. PRAMS site aggregate data indicate that on average 47.7% of women reported a normal pre-conception weight, slightly below the percentage in Pa. PA PRAMS Phase 7 (2012-2015) data indicate that black/African American women were least likely to report a normal weight prior to pregnancy (33%) as compared to white (52.7%) and Asian women (63.7%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Prenatal Care: Early and adequate prenatal care is important to improve outcomes for both mother and child. Prenatal care allows for identification of maternal disease and possible risk factors that may complicate pregnancy and/or birth. According to Pa, Birth Certificate data from 2012 to 2015, the percentage of women in Pa. who received early prenatal care (prenatal care beginning in the first trimester) decreased slightly from 72.4% (95% CI: 72.0, 72.9) in 2012 to 71.8% (95% CI: 71.3, 72.2) in 2015. However, this percentage did increase to 73.8% (95% CI: 73.3, 74.2) in 2016, making it challenging to establish a true trend. Women in 24 of the 67 counties in Pa. have received early prenatal care at a proportion exceeding the HP2020 goal of 77.9%. However, as a whole, Pennsylvania has not met the HP2020 goal to increase the proportion of pregnant women who receive prenatal care beginning in the first trimester to 77.9% (ODPHP, 2020). Pennsylvania falls short of meeting this goal for all ages and all races. Additionally, 2016 data show that health disparities exist as black/African American (63%, 95% CI: 61.8, 64.2), Hispanic (64.7%, 95% CI: 63.4, 66.0) and multi-race (65.1%, 95% CI: 62.7, 67.6) women were less likely to receive early prenatal care as compared to white (77.5%, 95% CI: 77, 78.1) and Asian/Pacific Islander (72.8%, 95% CI: 70.7, 74.9) women. Black/African American women were three times as likely to receive no prenatal care (3.7%, 95% CI: 3.5, 4.0) as compared to white women (1%, 95% CI: 0.9, 1.0). Focusing efforts among racial/ethnic minority women and in the 43 counties that remain below the HP2020 goal may be beneficial to improve the percentage of women receiving prenatal care within the first trimester (DOH, Birth Certificate Data, 2012-2016).

Prenatal care is considered adequate when it is initiated early and the number of visits received is consistent with the number recommended (Kotelchuck, 1994). PRAMS 2012-2015 data indicate that the percentage of women who received adequate prenatal care according to the Adequacy of Prenatal Care Utilization Index (APNCU or Kotelchuck Index) reached a four-year high in 2015 (74.8%), up from a low of 69.1% in 2013. Aggregated PRAMS data (Phase 7, 2012-2015) indicate that the percentage of women who nationally received adequate prenatal care in 2015 was 74.5%, which is very similar to Pa. Yet, Pa. still falls short of the HP2020 goal of having 77.6% of women receive adequate prenatal care (ODPHP, 2020). Additionally, PRAMS Phase 7 data (2012-2015) demonstrate that disparities in receipt of adequate prenatal care exist among racial/ethnic minorities, women of low socioeconomic status and women who are unmarried. Hispanic women were less likely than their non-Hispanic counterparts to have received adequate prenatal care (64.7% vs. 72.8%), and only 62.3% of black/African American women had adequate prenatal care as compared to 74.5% of white women reporting adequate prenatal care. Approximately, 63.2% of women who had a high school education or below had adequate prenatal care as compared to 77.7% of women who had a bachelor’s degree or higher. Women with a lower household annual income were consistently less likely to have had adequate prenatal care as compared to women with higher income; 63.2% of women with a household income <$15,0000/year had adequate prenatal care as compared to 78.1% of women with >$52,000/year. Finally, 67.1% of unmarried women reported adequate prenatal care as compared to 75.2% of married women (CDC, PRAMS, 2012-2015; DOH, PA PRAMS 2012-2015).

Dental Care During Pregnancy: Preventive dental care during pregnancy is recommended to maintain oral hygiene and health. The percentage of women who report having had a preventive dental visit during pregnancy via PRAMS has remained consistent from 2012 to 2015, with 54.6% of women reporting such a visit in 2012 and 54.7% reporting such a visit in 2015. Additionally, as of 2015, a higher percentage of women in Pa. (54.7%) have received a dental visit during pregnancy as compared to the PRAMS site aggregate percentage during 2012-2015 (48.3%). During PRAMS Phase 7 (2012-2015), mothers aged ≤ 19 years old (44.2%) were less likely to have had a dental cleaning during pregnancy as compared to older women (53.3% of women aged 20 to 34 and 61.7% of women aged 35 or older reported a cleaning). Asian women (43.4%) were less likely to report a dental cleaning by a dentist or dental hygienist during pregnancy as compared to white women (56.4%), and women with a household annual income between $15,0001 and $29,000 were less likely to have had a preventive dental visit during pregnancy (44.8%) as compared to women with a household annual income of $52,000 or higher (65.6%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS 2012-2015].

Postpartum Care: Continuation of maternal care is important for the mother and infant in order to monitor maternal recovery/healing following birth and to ensure that needed resources and services are available. Additionally, postpartum appointments provide an opportunity to assess maternal well-being (physical, emotional, psychological) and discuss health maintenance, chronic disease care, infant care and feeding, as well as sexuality, birth spacing and contraception, among other topics (American College of Obstetricians and Gynecology [ACOG], 2018). According to PRAMS Phase 7 data (2012-2015), the percentage of women in Pennsylvania who attend a postpartum care visit after birth has increased from 88.6% in 2012 to 91.5% in 2015, exceeding the HP2020 goal of 90.8% (ODPHP, 2020). The percentage of Pa. women reporting postpartum care (91.5%) exceeds the PRAMS aggregate of 89.7% in 2015. Yet, when looking at PRAMS Phase 7 data from 2012-2015 the percentage of women reporting a postpartum care visit is slightly lower among women aged 19 or less (84.9%) as compared to older women (90.2% among women aged 20 to 34; 90.7% among women aged 35 or older). Women of Hispanic ethnicity (83.9%) were also less likely to receive postpartum care as compared to non-Hispanic women (90.8%) during 2012-2015. Additionally, again when looking at PRAMS Phase 7 data (2012-2015), women with a high school education or lower (84.2%) were less likely to receive postpartum care as compared to women with higher educational attainment (91.1% of women with some college or an associate degree received postpartum care; 95.5% of women with a bachelor’s degree received postpartum care. Unmarried women were less likely to report receiving postpartum care (87.1%) as compared to married women (92.2%), and women with a household annual income of $15,000 or less (82.2%) were also less likely to have received postpartum care as compared to women with higher household annual income (i.e. 95.6% of women with a household annual income exceeding $52,000 received postpartum care) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Postpartum Contraception Use: Postpartum contraception aids mothers in avoiding unintended pregnancies shortly following birth. PRAMS Phase 7 data (2012-2015) shows that the percentage of Pa. women who had a live birth reporting postpartum contraception use has decreased from 79.7% in 2012 to 75.1% in 2015. A similar change is apparent in the PRAMS aggregate data from 2012 to 2015, albeit the percent change is slightly lower (80.5% reporting postpartum contraception in 2012 compared to 78.4% in 2015). However, Pennsylvania still far exceeds the HP2020 target of increasing the percentage of women who use postpartum contraception to 58.5% (ODPHP, 2020). Additionally, PA PRAMS 2012-2015 data showed that young mothers (≤19 years of age) were more likely to report having used a method of contraception during the postpartum period (84.4%) as compared to the mothers aged ≥35 years (68.9%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Risk Factors

Smoking and Alcohol Use During Pregnancy: Smoking during pregnancy can adversely affect the health of the mother and the development of her fetus. Maternal smoking may also result in increased risk of long-term health issues for the infant once born. Consumption of alcohol during pregnancy can also adversely affect the fetus and, in some cases, result in fetal alcohol syndrome.

PRAMS Phase 7 data (2012-2015) suggest that the percentage of women who reported smoking during the last three months of pregnancy has decreased from 12.6% in 2012 to 10.8% in 2015. A similar marked decline in the number of women who reported smoking during their final trimester is evident in the PRAMS 2012-2015 site aggregate data; 10.6% in 2012 compared to 8.8% reported smoking in 2015. PA PRAMS Phase 7 data (2012-2015) indicate that women with a household annual income <$15,000 were more likely to smoke during the last trimester (28.1%) as compared to women with higher household annual income (4.1% among women with a household annual income exceeding $52,000). Additionally, unmarried women (22.3%) were more likely to report smoking as compared to married women (5.3%), as were women with a high school education or less (20.3%) when compared to women with higher educational attainment (2.5%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Conversely, the percentage of women who reported consuming alcohol within the last trimester of pregnancy has increased slightly from 6.1% in 2012 to 8.0% in 2015 according to PA PRAMS 2012-2015 data. As of 2015, the percentage of women reporting alcohol consumption in the last three months of pregnancy in Pa. is the same as the percentage of women reporting such consumption in the PRAMS 2012-2015 site aggregate data (8.0%). During 2012-2015, Pa. women aged 35 and older were more likely to report alcohol consumption during pregnancy (10.5%) as compared to their younger counterparts (1.5%) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Pregnancy Weight Gain: The ACOG recommendation is that women gain weight during pregnancy in proportion with their pre-pregnancy BMI (ACOG, 2013). Gaining less or more than the recommended amount can adversely impact the development and long-term health of the infant, and, in the event too much weight is gained, may result in health challenges associated with increased bodyweight following pregnancy. As of 2015 in Pennsylvania, over half of women with a singleton birth reported gaining more than the recommended amount (54.8%) according to the PRAMS survey, whereas only 26.2% of women gained weight within the recommended amount during pregnancy and 19.0% gained too little. PRAMS 2012-2015 site aggregate data demonstrate a similar pattern in that, as of 2015, 48.9% of women with a singleton birth reported gaining more weight than recommended while only 29.5% were within recommendations. In contrast, Pa. women giving birth to twins were more likely to report that they had gained less than recommended (38.9%) based on their pre-pregnancy BMI (CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015).

Intimate Partner Violence During Pregnancy: Physical, sexual and psychological violence can result in trauma and lead to injury or death at any time, including during pregnancy. According to PA PRAMS 2012-2015 data, the percentage of Pa. women who reported experiencing physical violence at the hands of their partner or husband during pregnancy has decreased from 4.6% in 2012 to 2.1% in 2015. Similarly, 2.1% of women across PRAMS sites reported experiencing physical violence during pregnancy as of 2015. In 2015, 2.2% of women reported receiving threats from their husband/partner or feeling unsafe, and 2.2% of women reported feeling frightened for their safety due to their partner/husband's threats or anger during pregnancy. A slightly higher percentage of women (3.5%) reported feeling controlled by their husband/partner during pregnancy in 2015, and sexual abuse was least frequently reported, as only 0.6% of women reported being forced to take part in sexual activity when they did not want to during pregnancy (CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015).

Medication/Drug Use During Pregnancy: While certain medications can be used safely and effectively during pregnancy, including certain anti-depressants and pain relievers, less is known about use of drugs such as marijuana. During Phase 8 of PRAMS (2016-2019) Pa. respondents were asked about marijuana, anti-depressant and pain reliever use during pregnancy in a supplementary question. Given that only one year of data currently exists, trends over time cannot be characterized, and 2017 data serves solely as a baseline. As of 2017, 21.1% of women reported using marijuana during pregnancy. Only 7.3% of women reported taking anti-depressants during pregnancy and 4.9% reported taking pain relievers (DOH, PA PRAMS, 2017).

Caesarean Delivery Among Low-Risk First Births: Women who have had no prior births (nulliparous), carry to term (37+ weeks) and give birth to a singleton infant in vertex presentation are considered low-risk first births. In such scenarios, a caesarean delivery may not be indicated and, if elected or scheduled without medical necessity, may pose excess risk to both the mother and infant. Complications resulting from a caesarean section, including hemorrhage, may also become more likely with subsequent caesarean delivery. In 2017, 25.2% of Pa. women having a low-risk first birth had a c-section, which exceeds the HP2020 goal of 23.9% (ODPHP, 2020). Reducing the percentage of caesarean deliveries among low risk first births is recommended for improving health outcomes and quality of care (DOH, Birth Certificate Data, 2013-2017).

Morbidities

Gestational Diabetes: Gestational diabetes is diabetes that a woman develops for the first time during her pregnancy. Aggregate data across PRAMS sites indicate that 5.8% of women reported gestational diabetes in 2015 (CDC, PRAMS, 2012-2015).

Pennsylvania birth certificate data indicate that 5.8% of women had gestational diabetes in 2017 and, when stratified by age, women aged 35 and older were more likely to have gestational diabetes (9.0%) as compared to their younger counterparts (2.0% among women aged 19 and younger). Additionally, Asian/Pacific Islander women were more likely to have gestational diabetes (10%) as compared to women of other races (5.8% among white women, 4.2% among black women) [DOH, Birth Certificate Data, 2013-2017].

Gestational/Maternal Hypertension: Aggregate PRAMS 2012-2015 data indicate that 7.5% of women reported having hypertension prior to pregnancy in 2015 and 6.3% of women in Pa. reported having hypertension prior to pregnancy in 2015 according to PA PRAMS 2012-2015 data (CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015).

According to Pa. Birth Certificate data, 6.2% of women in Pennsylvania reported having gestational hypertension (developed during pregnancy) in 2017 and gestational hypertension was more frequently seen among young mothers aged 19 or less (7.5%) as compared to women aged 20 to 34 (6.0%) or older than 35 (6.9%). Black and African American women also were more likely to have gestational hypertension (8.9%) as compared to white (5.9%) and Asian (3.7%) women (DOH, Birth Certificate Data 2013-2017).

Antepartum Depression: Pregnancy may cause emotional changes which adversely affect maternal well-being. Depression during pregnancy (also called antepartum depression) is common and treatable. PA PRAMS data from 2015 indicates that 9.8% of women reported asking a health care worker for help with depression during pregnancy and 8.4% of women in Pennsylvania were told by a health professional that they had depression. Although the percentage of women told they had depression during pregnancy as of 2015 (8.4%) has decreased since 2013 (10.1%), there is no apparent trend between 2012 and 2015. During PRAMS Phase 7 (2012-2015), women aged 19 or under (12.8%) were more likely to report being told they had depression during pregnancy as compared to older women (8.7% among women aged 20 to 34, 8.4% among women aged 35 and older) [CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015].

Mortality

Maternal Mortality: Pregnancy-related death is defined as the “death of a woman while pregnant or within 1 year of the end of a pregnancy – regardless of the outcome, duration or site of the pregnancy – from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes” (CDC, 2020). As such, pregnancy-related deaths occur during pregnancy or within one year of its end. In Pa., the rate of pregnancy-related death was 13.3 pregnancy-related deaths per 100,000 live births during 2011-2015.While improvements to reporting, data quality and review of maternal deaths are ongoing, disparities persist. Black/African American women are over two times more likely to die a pregnancy-related death as compared to white women in Pa. (Pregnancy Mortality Surveillance System, 2009-2015).

The NOM for maternal mortality focuses on pregnancy-related deaths within 42 days of the end of pregnancy. Similarly, HP2020 aims to reduce pregnancy-related deaths within 42 days to 11.4 pregnancy-related deaths per 100,000 live births (ODPHP, 2020). Given the difference in definition (death within one year of pregnancy vs. death within 42 days), it was not possible to directly compare the pregnancy-related death rate presented above to the HP2020 goal.

Perinatal/Infant Health

Population Demographics

Infants are children in their first year of life – within 365 days of birth (U.S. DHHS, 2015, Appendix, p.99). In 2017, there were 137,771 live births in Pa. The general fertility rate in Pa. has gradually decreased over the last three years from 59.0 live births per 1,000 women between the ages of 15 and 44 in 2014 to 57.8 births per 1,000 women between the ages of 15 and 44 in 2017 (DOH Birth Statistics, 2017).

Wellness and Access to Health Care

Breastfeeding: Exclusive breastfeeding for six months is recommended for all infants, as it aids in the development of the infant's immune system and reduces the likelihood of illness and disease later in life. Breastfeeding is also beneficial for maternal health. As of 2016, 81.1% (95% CI: 80.6, 81.5) of infants were ever breastfed according to Pa. Birth Certificate data and the number of women breastfeeding their infants increased by 8.0% from 73.1% (95% CI: 72.7, 73.6) in 2012 to 81.1% in 2016. However, disparities exist given that, as of 2016, black/African American (74.8%, 95% CI: 73.6, 76.1) and multi-racial (76.6%, 95% CI: 74, 79.2) infants were less likely to be breastfed as compared to white (81.7%, 95% CI: 81.2, 82.3) and Asian/Pacific Islander (91.4%, 95% CI: 89.1, 93.8) infants. Additionally, approximately two-thirds of Pa.'s counties (42 of 67) fall below the HP2020 goal (ODPHP, 2020). Breastfeeding in Pa. also differs by maternal age. Infants born to women aged 20 to 24 were less likely to be breastfed as compared to infants born to women between the ages of 30 and 34; 75% (95% CI: 73.9, 76.0) of infants born to women aged 20 to 24 were ever breastfed as compared to 85.4% (95% CI: 84.5, 86.3) of infants born to women aged 30 to 34 (DOH, Birth Certificate Data, 2012-2016).

As of 2015, National Immunization Survey data from Pa. indicate that 48.9% (95% CI: 42.2, 55.6) of mothers reported breastfeeding their infant exclusively through three months, while only 25.6% (95% CI: 20.1, 31.1) reported exclusive breastfeeding through six months. Nationally, the percentage of mothers reporting exclusive three-month (46.9%, 95% CI: 45.5, 48.3) and six-month breastfeeding (24.9%, 95% CI: 23.7, 26.1), respectively, is slightly lower but similar. As of 2015, Pa. has met the HP2020 goals for three-month (46.2%) and six-month (25.5%) exclusive breastfeeding (ODPHP, 2020; CDC, NIS 2015).

Keystone 10 Facilities: As of 2018, 77 of the 87 hospitals and birthing centers in Pa. (94%) are participating in the Keystone 10 initiative, a quality improvement breastfeeding initiative aimed at improving protection, promotion and support of breastfeeding. Of the 10 steps required to implement all of the recommended practices to improve breastfeeding, 83% of facilities have achieved at least one step and, on average, most facilities had completed at least three steps as of 2018 (DOH, Keystone 10 data, 2016-2018).

Newborn Screening: Infants born in Pa. are screened for heritable disorders, including metabolic, endocrine, hemoglobin and heart disease, as well as hearing loss. Many of these are heritable disorders which are treatable but require early detection and intervention. The goal is to screen all infants born in Pa. Available data from 2017 indicated that approximately 97.8% of infants born in Pa. were screened, only 2.2% away from screening the same number of infants as there were live births. Although Pa. was close to reaching 100% screening in 2017, the 2.2% represents nearly 3,000 unscreened infants (DOH, Newborn Screening data, 2017).

The amount of time between sample collection and receipt of that sample by the laboratory is an important indicator for newborn screening, as it also impacts how quickly results can be received and reported out. This indicator, often reported in hours, measures the amount of time from when the filter paper is collected from the infant to the time it is received at the lab. If specimens reach the lab within 24 to 48 hours, that enables prompt reporting. In Pa. in 2018, 74% of collected samples reached the laboratory within the recommended 48 hours. This is an improvement from 2014 when only 64% of specimens reached the lab within the recommended 48 hours (DOH, Newborn Screening Data, 2017-2018).

Reporting of screening results should occur promptly. Although there is no federal benchmark for prompt reporting of newborn screening results, this is an important indicator in Pa. Combined data from 2017-2018 show that the average time from birth to report out in Pa. is approximately 9.4 days. Data from 2018 indicate that the average report out time is slightly longer for black/African American newborns (11.9 days) as compared to their white counterparts (8.7 days) [DOH, Newborn Screening Data, 2017-2018].

While newborn screening is an important component of care following birth, it is most successful if follow-up services are received equitably and in a timely fashion for all newborns. To best promote positive outcomes, needed diagnostic work-up and treatment should begin as quickly as possible. Follow-up in the form of a “call-out” to a physician following screening is considered timely if done within five days for a time-critical condition and within seven days for all other conditions. While all newborns meriting time-critical call-outs did receive follow-up in 2018, only 72.8% of newborns received timely follow-up in 2018. Similarly, only 70% of non-time critical callouts were timely in 2018 (DOH, Newborn Screening data, 2017-2018).

Risk Factors

Preterm Birth: Babies born preterm (<37 weeks) are at a greater risk of immediate and long-term health problems and complications, some of which may be life-threatening. While the percent of preterm births in Pa. has remained constant and at or 0.1% below the HP2020 goal of reducing the percentage of preterm births to 9.4% from 2012 to 2016, disparities exist related to maternal age and race (ODPHP, 2020). Pa. Birth Certificate data from 2016 indicate that the percentage of preterm births was higher for mothers who are aged 17 or below (10.7%, 95% CI: 9.2, 12.3) and those older than 35 years old (10.3%, 95% CI: 9.9, 10.8) as compared to women between the ages of 20 and 29 (9.3%, 95% CI: 8.9, 9.7 among women aged 20 to 24; 8.7%, 95% CI: 8.4, 8.9 preterm births among women between the ages of 25 and 29). In 2016, the percentage of preterm births for black/African American infants was consistently higher (13.2%, 95% CI: 12.6, 13.7) as compared to white infants (8.5%, 95% CI: 8.4, 8.7) and this trend was consistent for all maternal ages. Similarly, multi-race (10.7%, 95% CI: 9.7, 11.6) and Hispanic (9.9%, 95% CI: 9.4, 10.3) infants were also more likely to be preterm as compared to white (8.5%, 95% CI: 8.4, 8.7) and Asian/Pacific Islander (8.3%, 95% CI: 7.6, 9.0) infants. Although, statewide, Pa. is meeting the HP2020 goal, disparities persist among racial/ethnic minorities and by region (DOH, Birth Certificate Data, 2012-2016).

Low Birth Weight Delivery: Low (<2,500 grams) and very low (<1,500 grams) birth weight infants may be at greater risk of experiencing physical and developmental health problems or dying within the first year of life. In Pa., the percentage of low birth weight deliveries has remained relatively constant from 2012 (8.1%, 95% CI: 8.0, 8.3) to 2016 (8.2%, 95% CI: 8.1, 8.4). Similarly, the percentage of very low birth weight births has remained nearly unchanged from 2012 to 2016 and is at 1.5% (95% CI: 1.4, 1.5) as of 2016. Pa. slightly exceeds the

HP2020 goal to reduce low birth weight deliveries to only 7.8% and is also above the HP2020 goal of reducing the percentage of very low birth weight births to 1.4% (ODPHP, 2020). As of 2016, disparities exist as low birth weight deliveries are more common among women with a maternal age younger than 24 or older than 35 years old and among black/African American (13.9%, 95% CI: 13.4, 14.5), multi-race (10.2%, 95% CI: 9.3, 11.1), Hispanic (9.0%, 95% CI: 8.5, 9.5), and Asian/Pacific Islander (8.7%, 95% CI: 8.0, 9.5) mothers as compared to white women (6.9%, 95% CI: 6.7, 7.0). Similarly, in 2016, more than twice as many black/African American women had very low birth weight infants (3.2%, 95% CI: 3.0, 3.5) as compared to white women (1.1%, 95% CI: 1.0, 1.1) [DOH, Birth Certificate Data, 2012-2016].

Sleep Position: The American Academy of Pediatrics has recommended that infants be placed to sleep on their back since 1992 and, as of 2011, also adopted the recommendation that infants be placed on a separate, firm sleep surface without loose bedding (AAP, 2020). Appropriate sleep positioning is important to reduce the risk of sleep-related death among infants. The percentage of PA PRAMS respondents who report most often placing their infants to sleep on their backs reached a four-year high in 2015 (84.0%) and has exceeded the HP2020 target of having 75.8% of infants being placed on their backs (ODPHP, 2020). Comparatively, only 78.4% of women across PRAMS sites reported placing their infant on their back to sleep as of 2015. However, during PRAMS Phase 7 in Pa., black/African American mothers (69.6%) less frequently reported placing their infants on their backs to sleep as compared to white women (82.8%). Additionally, mothers aged 19 or below (75.2%) less frequently reported placing their infants on their backs to sleep as compared to older women (80.3% of women aged 20 to 34 and 83.9% of women aged 35 and older). In 2015, 49.2% of PA PRAMS (2012-2015) respondents reported that their infant always slept on a separate sleep surface, the lowest percentage since 2012 (49.5%) and a decrease from 2014 (52.9%).

Black/African American (33.3%) and Asian (32.8%) women were least likely to report placing their infant on a separate sleep surface during PRAMS Phase 7 (2012-2015) as compared to white women (55.6%). Similarly, only 40.3% of PA PRAMS respondents reported placing their infant in a crib or on a firm, separate surface to sleep as of 2015 (also a four-year low). According to PRAMS data, the percentage of mothers who report putting their child to sleep without loose bedding (i.e., blankets, pillows, plush toys) has consistently increased from 51.6% in 2012 to 63.7% in 2015, exceeding the PRAMS site aggregate percentage in 2015, which was 60.7% (CDC, PRAMS, 2012-2015; DOH, PA PRAMS, 2012-2015).

Morbidities

Neonatal Abstinence Syndrome: The epidemic resulting from prescription opioid and substance use is ongoing in Pa. and has resulted in a public health crisis with thousands of drug-related overdoses occurring annually. In response, Pennsylvania Governor Tom Wolf issued a statewide disaster declaration in January 2018 that has been renewed multiple times (Commonwealth of Pa., 2019). Neonatal abstinence syndrome (NAS) is withdrawal experienced by a newborn due to prenatal substance exposure. Since SFY 2008-2009, the rate of infants born with NAS per 1,000 hospital births in Pa. has steadily increased, reaching a rate of 15 infants born with NAS per 1,000 hospital births in SFY 2015-2016, nearly triple the state rate in SFY 2008-2009, which was 5.1. As of SFY 2016, rates of NAS are highest among white infants and those born into a household with a median income below $60,000. Additionally, Greene County has the highest rate of NAS in Pa., at 76 infants born with NAS per 1,000 hospital births, five times higher than the state rate. There is no HP2020 target for NAS given that the goal is 100% abstinence from illicit substance use and/or substance use among pregnant women (PHC4, 2018).

Mortality

Perinatal Mortality: Perinatal mortality refers to the death of a fetus occurring at or over 28 weeks of gestation up to within seven days of birth. The HP2020 goal is 5.9 perinatal deaths per 1,000 live births plus fetal deaths (ODPHP, 2020). Pa. has not met this goal from 2012 to 2016; the rate in 2016 was 6.7 perinatal deaths per 1,000 live births plus fetal deaths. Information related to maternal age and race/ethnicity was not available and much of the county-level data was suppressed due to low numbers, making it difficult to identify disparities (DOH, Birth Certificate Data, 2012-2016).

Infant Mortality: Infant mortality is a well-established measure of population health and the quality of care in a health system. While Pa. is close to meeting the HP2020 target for infant mortality, racial disparities exist. The overall infant mortality rate in Pa. as of 2016 is 6.1 per 1,000 live births (95% CI: 5.7, 6.6), which is close to the national target of 6.0 (ODPHP, 2020). However, 2016 data indicates that the rates for black/African American (14.6, 95% CI: 12.8, 16.3), multi-race (8.8, 95% CI: 6.1, 11.6), and Hispanic (7.4, 95% CI: 6.1, 8.8) are well above the target and greatly exceed the infant mortality rate among white infants (4.6) [DOH, Death Certificate Data, 2012-2016].

Preterm-related Mortality: Preterm-related death is the leading cause of death among infants in Pa. Pa. has seen a decrease in the preterm-related mortality rate over the last four years (2012-2015) according to data available from the National Vital Statistics System in Pa. reaching a low of 248.1 per 100,000 live births in 2014 (as compared to 287 per 100,000 live births in 2012). In 2015, the rate increased to 252.4 per 100,000 live births. While this is not the highest rate in the most recent five-year period, it is the first time the rate increased in Pa. between 2012 and 2015 (CDC, CDC Wonder 2012-2016).

Neonatal Mortality: Neonatal deaths are those that occur within the first month of life (under 28 days from birth). The neonatal mortality rate in Pa. has decreased since 2012 (5.0, 95% CI: 4.6, 5.3) and, as of 2016, is 4.4 deaths per 1,000 live births (95% CI: 4.1, 4.8), which is above the HP2020 goal of 4.1 (ODPHP, 2020). Significant disparities exist across racial groups; the rates are highest among black/African American infants (10.2, 95% CI: 8.8, 11.7) followed by Hispanic (5.7, 95% CI: 4.5, 6.9), multi-race (5.2, 95% CI:), white (3.3, 95% CI: 3.1, 7.3), and Asian/Pacific Islander (1.9, 95% CI: 0.8, 2.9) infants (DOH, Death Certificate data, 2012-2016).

Post Neonatal Mortality: Post neonatal deaths are those that occur when the infant is between 28 and 364 days old. The HP2020 goal is 2.0 deaths per 1,000 live births. Overall, Pa. has met or exceeded the HP2020 goal for this measure consistently from 2012 to 2016. The state post neonatal mortality rate has hovered around 1.7 deaths per 1,000 live births from 2013 to 2016. However, according to 2016 data, disparities exist. The post neonatal mortality rate is higher for black/African American (4.3, 95% CI: 3.4, 5.2) and multi-race (3.6, 95% CI: 1.9, 5.4) infants as compared to white infants (1.3, 95% CI: 1.0, 1.5) [DOH, Death Certificate Data, 2012-2016].

Sudden Infant Death Syndrome (SIDS): Sudden infant death syndrome (SIDS) is a common cause of death in infants from one month to one year. The HP2020 goal is to reduce deaths attributed to SIDS to 0.50 deaths per 1,000 live births (ODPHP, 2020). Overall, Pa. has met the HP2020 goal for this measure since 2012. The 2016 rate of SIDS in Pa. is 0.40 deaths per 1,000 live births (95% CI: 0.3, 0.5). However, 2016 data show that disparities still exist between white infants who have a SIDS death rate of 0.3 deaths per 1,000 births (95% CI: 0.2, 0.4) and black/African American infants with a rate of 0.8 deaths per 1,000 births (95% CI: 0.4, 1.2) [DOH, Death Certificate Data, 2012-2016].

Sudden Unexpected Infant Death (SUID): Sudden unexpected infant death (SUID) includes deaths attributed to SIDS, accidental suffocation or strangulation in a sleeping environment, and other unknown causes. As of 2015, there were 102.8 SUID deaths in Pa. per 100,000 live births, which is higher than the HP2020 goal of 84 SUID deaths per 100,000 (U.S. DHHS, 2016). When stratified by race and ethnicity, black and African American infants are 2.5 times more likely to die of SUID than white infants in Pa. (DOH, CDR Report, 2018).

Child Health

Population Demographics

According to HRSA and the Title V guidance, children are between the ages of 1 and 21 (U.S. DHHS, 2015, Appendix, p. 98). As of 2017, Pa. is home to over 2.6 million children between the ages of 0 and 17 (U.S. Census Bureau, ACS 5-Year, 2013-2017). Approximately 31.9% of children are between the ages of 0 and 5, 33.4% of children between the ages of 6 and 11 and 34.6% of children between the ages of 12 and 17 (U.S. Census Bureau, ACS 5-Year, 2013-2017).

Wellness and Access to Health Care

Child Well Visit: Preventive medical visits are important for children in order to monitor growth and development. NSCH data from 2016-2017 indicate that 86.3% (95% CI: 83.0, 89.1) of children aged 0 to 17 in Pa. had at least one preventive check-up with a health care professional, which is slightly higher than the national average of 82.2% (95% CI: 81.5, 83.0). Well visits were most common among children aged 0 to 5 (89.6%, 95% CI: 83.8, 93.5), but this percentage decreased to 83.7% (95% CI: 76.5, 89.0) among children aged 6 to 11 and 85.7% (95% CI: 80.3, 89.8) among adolescents aged 12 to 17. When considering all children surveyed by the NSCH (ages 0 to 17), children speaking a language other than English were least likely to have had a well child visit (58.9%, 95% CI: 41.6, 74.4) as compared to English-speaking children (89.4%, 95% CI: 86.4, 91.8). CSHCN were also more likely to have had a child well visit than their counterparts without special health care needs (93.3%, 95% CI: 85.8, 97 among CSHCN vs. 84.7%, 95% CI: 80.8, 88.0 among children without special health care needs) [DRCCAH, 2016-2017].

As of 2016-2017, 73.5% (95% CI: 69.6, 77.1) of Pa. parents surveyed via the NSCH reported always receiving specific, needed information about their child's health, learning, development or behavior from a doctor or health care provider. Although Pa. is slightly below the national average (75.7%, 95% CI: 74.9, 76.5), it does exceed the HP2020 goal of 52.8% (ODPHP, 2020). Parents of black/African American children (65.5%, 95% CI: 49.0, 78.9) were less likely to report receiving needed information as compared to parents of white children (76.6%, 95% CI: 72.9, 80.0). Additionally, parents of CSHCN (67.2%, 95% CI: 58.8, 74.6) were less likely to report receiving needed information regarding their children as compared to parents of children without special health care needs (75.2%, 95% CI: 70.7, 79.2). However, even after stratification, these percentages still exceed the HP2020 goal (DRCCAH, 2016-2017).

Health Insurance: The goal is to reduce the rate of all people and adolescents and children aged 0 to 17 who are uninsured to 0%. Children who have health insurance are known to have better access to care and, by extension, better health outcomes. According to the American Community Survey, the percentage of children 0 to 17 who are uninsured in Pa. increased from 4.1% in 2015 to 4.4% in 2016. This trend is inconsistent with the 0.3% decrease in the uninsured rate seen at the national level (4.80% in 2015 to 4.50% in 2016). As of 2016, white, Hispanic and American Indian adolescents were disproportionately uninsured as compared to other racial/ethnic groups, as were adolescents in Lancaster and Indiana counties. When compared to the HP2020 goal of 0% uninsured, it is evident that access to health insurance among children and adolescents remains important in Pa. (ODPHP, 2020; U.S. Census Bureau, ACS 1-Year, 2015-2016).

The NSCH further characterizes “adequacy” of health insurance by assessing whether the child’s health insurance covers needed services and providers at a reasonable cost. As of 2016-2017, 77.9% (95% CI: 74.7, 80.8) of children aged 0 to 17 were reported as having adequate health insurance in Pa., whereas only 74.4% (95% CI: 73.6, 75.1) had adequate health insurance nationally. CSHCN were least likely to have “adequate” health insurance in Pa. (68.6%, 95% CI: 60.5, 75.7) as compared to children without special health care needs (80.2%, 95% CI: 76.8, 83.2) [DRCCAH, 2016-2017].

Medical Home: A medical home is a team-based health care delivery system which aims to provide coordinated and comprehensive care (U.S. DHHS, 2015, Appendix p. 108). As of 2016-2017, 48.5% (95% CI: 44.7, 52.3) of children under the age of 18 in Pa. were reported to be receiving coordinated, ongoing comprehensive care within a medical home via the NSCH survey, a percentage that is nearly identical to the national average of 48.6% (95% CI: 47.7, 49.5). However, both the state and national percentages are below the HP2020 goal of having 63.3% of children under 18 receiving care via a medical home (ODPHP, 2020). Children under 18 that spoke a language other than English were least likely to have a medical home (14.6%, 95% CI: 7.9, 25.5) as compared to children who spoke English (52.2%, 95% CI: 48.3, 56.1). Having a medical home was also more common among children aged 6 to 11 (51.4%, 95% CI: 44.4, 58.5) as compared to children aged 0 to 5 (48.9%, 95% CI: 42.0, 55.7) or 12 to 17 (45.0%, 95% CI: 39.6, 50.5) [DRCCAH, 2016-2017].

Mental/Behavioral Health Treatment: Mental health is an important component of a child’s overall health. Early identification and treatment of mental/behavioral health issues is important. According to NSCH data, as of 2016-2017, 11.8% (95% CI: 9.5, 14.7) of children aged 3 through 17 reported receiving treatment or counseling from a mental health care professional and 1.2% (95% CI: 0.7, 1.9) of children reported not receiving needed mental health care in Pa. Nationally, 9.8% (95% CI: 9.3, 10.3) of children received treatment or counseling for mental health, while 2.4% (95% CI: 2.1, 2.8) reported not receiving needed mental/behavioral health care. The percentage of children who reported not receiving needed mental health care in Pa. is half the national percentage (DRCCAH, 2016-2017).

Preventive Dental Visit: Oral health is an important aspect of well-being among children. As of 2016-2017, 80.5% (95% CI: 76.9, 83.6) of children aged 1 through 17 in Pa. reported seeing an oral health care provider for preventive care via the NSCH, which exceeds the national average of 79.5% (95% CI: 78.7, 80.2). However, children aged 1 to 5 (58.4%, 95% CI: 50.9, 65.5) were less likely to have had a preventive dental visit as compared to older children (90.4%, 95% CI: of children aged 6 to 11 had a dental visit and 89.7%, 95% CI: 85.2, 93.0 of children aged 12 through 17 had a dental visit). Additionally, children speaking a language other than English (63.9%, 95% CI: 45.9, 78.8) were less likely to have received preventive dental care as of 2016-2017 when compared to children who spoke English (82.2%, 95% CI: 78.9, 85.1) [DRCCAH, 2016-2017].

Self-reported Health: Self-reported health is considered a strong indicator of wellness and quality of life. As of 2016-2017, 92.3% (95% CI: 89.7, 94.3) of children aged 0 through 17 were reported to have excellent or very good health via the PA NSCH, whereas only 89.8% (95% CI: 89.1, 90.4) of children were reported to have excellent or very good health nationally. Although Pa. exceeds the national average, disparities exist, as Hispanic children (81.4%, 95% CI: 68.4, 89.8) were less likely to be reported as having very good or excellent health as compared to Non-Hispanic, white children (94.9%, 95% CI: 92.8, 96.4). Notably, children with special health care needs were less likely to be reported as having very good or excellent health in 2016-2017, with only 75.9% (95% CI: 67.9, 82.5) reporting such a health status as compared to 96.2% (95% CI: 93.6, 97.8) among children without special health care needs (DRCCAH, 2016-2017).

Developmental Screening: Identification of developmental delays via early screening is important for the health of children and the well-being of their families. Data from the 2016-2017 NSCH surveys indicate that 26.1% (95% CI: 18.7, 35.2) of children between the ages of 9 and 35 months received developmental screening via a parent-completed tool in Pa., whereas, on average, 31.1% (95% CI: 28.9, 33.4) of children received such screening nationally. Sociodemographic data were not readily available for this indicator, so stratification was not possible (DRCCAH, 2016-2017).

Immunization: The combined seven-vaccine series aims to induce active immunity against once common childhood diseases including diphtheria, tetanus and pertussis (DTaP), Poliomyelitis (polio), measles, mumps and rubella (MMR), Haemophilus influenza B (HiB), hepatitis B (HepB), varicella, and Streptococcus pneumoniae (PCV). According to the National Immunization Survey, the percentage of Pa. children aged 19 to 35 months who received the combined seven-vaccine series as of 2017 was 70.4% (95% CI: 63.5, 77.3), which is lower than in 2015 (72.8%, 95% CI: 67.0, 78.6) and 2016 (73.7%, 95% CI: 67.8, 79.6). Data from 2017 indicate that Asian/Pacific Islander and Hispanic children have a higher percentage of vaccination (80.0%, 95% CI: 65.4, 94.6 and 88%, 95% CI: 80.6, 95.4, respectively) in Pa., while white (67.8%, 95% CI: 58.4, 77.2) and black/African American (55.4%, 95% CI: 36.5, 74.3) children were less likely to have received the seven-vaccine series (CDC, NIS 2015-2017).

Seasonal influenza vaccination coverage among children aged 6 months to 17 years reported via the National Immunization Survey for the 2017-2018 flu season increased in Pa. to a four-year high of 65.3% (95% CI: 62.4, 68.2), exceeding the national average of 57.9% (95% CI: 57.2, 58.6) influenza vaccine coverage. Neither Pa. nor the nation are meeting the HP2020 goal of 70% influenza vaccine coverage. Nationally, seasonal influenza vaccination appears to be following a negative trend (59.3% in 2014-15 to 57.9% in 2017-18); that negative trend is not reflected in Pa. data. However, black/African American children have the lowest percentage of influenza vaccine coverage in Pa. at 44.3% (95% CI: 36.2, 52.4) as of the 2017-18 season (CDC, NIS 2014-2017).

Physical Activity: Regular physical activity among children can result in increased likelihood of positive health outcomes across the life course. As of 2016-2017, 28.8% (95% CI: 22.8, 35.7) of children aged 6 to 11 years reported engaging in at least 60 minutes of physical activity everyday via the PA NSCH. Similarly, 27.9% (95% CI: 26.5, 29.4) of children aged 6 to 11 reported engaging in daily physical activity nationally. When considering all children surveyed in the NSCH (ages 6 to 17), non-Hispanic black/African American children (7.7%, 95% CI: 2.8, 19.2) were least likely to report daily physical activity as compared to white, Non-Hispanic children (27.7%, 95% CI: 23.0, 33.0) and CSHCN (17.6%, 95% CI: 12.6, 24.1) were least likely to report participating in 60 minutes of physical activity daily as compared to children without special health care needs (26.7%, 95% CI: 21.9, 32.2) [DRCCAH, 2016-2017].

Risk Factors

Adverse Childhood Experiences (ACEs): Adverse childhood experiences (ACEs) are events that cause stress or trauma in a child’s life and may impact health outcomes and well-being across the life course. The NSCH asks parents whether their child has experienced one of the following ACEs: 1) Parent or guardian divorce or separation; 2) Death of parent or guardian; 3) Jail time for parent or guardian; 4) Witnessed/heard violence between parents; 5) Victim or witness of neighborhood violence; 6) Lived with someone with mental illness; 7) Lived with anyone with a drug/alcohol problem; 8) Unfair treatment/judgement because or race/ethnicity; 9) Hard to get by on family’s income. As of 2016-2017 24% (95% CI: 20.8, 27.6) of children aged 0 to 17 had experienced at least one ACE, and 19.2% (95% CI:16.4, 22.4) had experienced two or more in Pa. Nationally, the percentage of children who have experienced an ACE is comparable (24.6%). Disparities exist as the percentage of non-Hispanic, black children who have experienced an ACE (38.7%, 95% CI: 25.3, 54.1) or two or more ACEs (33.7%, 95% CI: 21.2, 49.0) is higher than non-Hispanic white children (20.6%, 95% CI: 17.4, 24.2 of white children reported one ACE, 14.7%, 95% CI: 12.2, 17.7 reported two or more). Similarly, there was a higher percentage of CSHCN who had experienced two or more ACEs (33%, 95% CI: 26.1, 40.7) as compared to children without special health care needs (15.9%, 95% CI: 12.9, 19.4) [DRCCAH, 2016-2017].

Bullying: According to 2016-2017 NSCH data, 19.0% (95% CI: 15.9, 22.5) of children aged 6 to 17 were reported as having experienced bullying in Pa., a percentage that is slightly below the national average of 21.7% (95% CI: 20.9, 22.5). Bullying was more common among youth aged 12 to 17 (20.9%, 95% CI: 16.6, 26.0) than among youth aged 6 to 11 (17.2%, 95% CI: 13.1, 22.4). A higher percentage of CSHCN were bullied (34.1%, 95% CI: 27.0, 42.0) as compared to children without special health care needs (14.2%, 95% CI: 10.9, 18.2) [DRCCAH, 2016-2017].

Environmental Tobacco Smoke Exposure: According to 2016-2017 data, 19.2% (95% CI: 16.2, 22.6) of children aged 0 to 17 in Pa. were living in a household with someone who smoked, whereas 15.5% (95% CI: 14.9, 16.1) of children were living in such a household nationally. Living in a household with someone who smokes was more commonly reported among Hispanic children (24.5%, 95% CI: 14.0, 39.2) as compared to non-Hispanic white children (18.3%, 95% CI: 15.2, 22.1), and a higher percentage of children 6 to 11 years of age lived in a household with a smoker (at 21.9%, 95% CI: 16.0, 29.3) as compared to children aged 0 to 5 (16.7%, 95% CI: 12.0, 22.7) and 12 to 17 (18.9%, 95% CI: 15.2, 23.4) [DRCCAH, 2016-2017].

Morbidities

Non-fatal Injury Hospitalizations: Non-fatal injuries which are severe and require hospitalization can develop into long-term health issues and impact the quality of life of children. According to Health Care Cost and Utilization Project (HCUP) data from state inpatient databases, the rate of hospitalization for non-fatal injury per 100,000 children aged 0 to 9 in Pa. decreased from 185.6 in 2011 to 153.4 in 2014. As of 2014, the national rate was 146.0, suggesting that the rate of hospitalizations for non-fatal injury in Pa. is slightly higher (PHC4 2019).

Tooth Decay: Tooth decay is a preventable condition that is common among children. As of 2016-2017, 12.0% (95% CI: 9.4, 15.2) of children aged 0 to 17 reported having had tooth decay or a cavity in the past year via the PA NSCH – a percentage that is only slightly above the national average (11.7%, 95% CI: 11.1, 12.4). Tooth decay was more common among children aged 6 to 11 (16.4%, 95% CI: 11.5, 22.8) as compared to children aged 1 to 5 (8.3%, 95% CI: 4.8, 14.1) and 12 to 17 (10.6%, 95% CI: 6.8, 16.0). In Pa., tooth decay was also more common among CSHCN (17.5%, 95% CI: 11.5, 25.9 vs. 10.6%, 95% CI: 7.8, 14.2 among children without special health care needs) [DRCCAH, 2016-2017].

Mortality

Child Mortality: Pa. aims to reduce the rate of mortality among children aged 1 to 9 years. The HP2020 goal is to reduce the rate of mortality among children aged 1 to 4 years to 26.5 deaths per 100,000 population and to 12.4 deaths per 100,000 among children aged 5 to 9 years (ODPHP, 2020). In both age groups, Pa. has met this goal every year for the past six years (2012 to 2017). For the 1 to 4 age group, Pa. reached a six-year high with a mortality rate of 26.3 per 100,000 in 2016. However, in 2017, this rate dropped to the lowest point in six years in Pa. at 19.5 child deaths per 100,000. For the 5 to 9 age group, Pa. has remained relatively steady and finished the six-year period in 2017 with a child mortality rate of 11.7 per 100,000, only slightly higher than in 2012 when the child mortality rate for ages 5 to 9 was 11.1 per 100,000 (CDC, CDC Wonder 2012-2017).

Child Death Review: Child death review is an example of a successful collaboration between the DOH and local Child Death Review (CDR) teams. The information captured during the review of a child death can be used to develop prevention strategies to reduce the number of preventable deaths. As such, the percentage of total deaths reviewed annually serves as an indicator of the agency’s capacity to protect children’s health. Of the 2,050 deaths among persons 21 years and younger in Pa. in 2015, 1,206 (58.8%) were reviewed. Comparatively, 72% of deaths were reviewed in Pa. in 2014 and 75.2% in 2013, suggesting that the percentage of deaths reviewed in Pa. has decreased over time. Of the 2015 deaths reviewed in Pa., infant deaths accounted for 45.2%, deaths of adolescents aged 15 to17 years accounted for 9.0% and deaths of young adults aged 18 to 21 accounted for 30.5%. Of the 2015 deaths reviewed in Pa., a higher percentage were male than female (61.8% vs. 38.2%) and a higher percentage were white children (55.5%) than black/African American children (34.2%) and Asian/Pacific Islander children (3.6%) [National Center for Fatality Review, Pa. data, 2011-2015].

Additionally, in Pa. in 2015, 70.7% of the total deaths attributed to external causes were reviewed, the highest percentage since 2011. Given that deaths attributed to external causes are thought to be most preventable, review of these deaths may contribute to prevention strategies that can be implemented in the future (National Center for Fatality Review, Pa. data, 2011-2015).

Adolescent Health

Population Demographics

Adolescence is the period of growth and development between childhood and adulthood. For the purpose of this report, adolescents are youth between the ages of 12 and 21.

Wellness and Access to Health Care

Immunization: The human papillomavirus (HPV) vaccine protects against cancers caused by HPV infection. Two to three doses of HPV vaccine are recommended for youth depending on the age at which the series is started and the timing of the doses (CDC, March 2020). According to NIS-Teen data from 2017, 67.3% (95% CI: 62.3, 72.3) of adolescents aged 13 through 17 years in Pa. received at least one dose of the HPV vaccine and 57.5% (95% CI: 52.3, 62.7) received at least two doses of HPV vaccine. The HP2020 goal is to increase the percentage of male and female adolescents aged 13 to 15 who receive two or three doses of HPV to 80% (ODPHP, 2020). Given that only 57.5% Pa. adolescents aged 13 to 17 reported receiving at least two doses as of 2017, Pa. is likely not meeting the national target (CDC, NIS-Teen 2015-2017).

The Tdap vaccine is often given as a booster immunization to adolescents or adults to provide continued protection against tetanus, diphtheria and pertussis following receipt of the DTaP during childhood (CDC, January 2020). The HP2020 goal is to increase the percentage of adolescents aged 13 through 17 years who have received the Tdap booster vaccine (ODPHP, 2020). In 2017, 90.6% (95% CI: 87.2, 94.0) of adolescents ages 13 to 17 in Pa. received at least one dose of the Tdap vaccine, exceeding the HP2020 goal of 80% (CDC, NIS-Teen 2015-2017).

The CDC recommends routine meningococcal conjugate vaccination for preteens and teens aged 11 to 12 years old and a booster at 16 years of age (CDC, July 2019). The HP2020 goal is to increase the percentage of adolescents aged 13 through 15 years who receive at least one dose of the meningococcal conjugate vaccine to 80% (ODPHP, 2020). In 2017, NIS-Teen data indicate that 93.4% (95% CI: 90.8, 96.0) of adolescents ages 13 to 17 in Pa. had received at least one dose of the meningococcal conjugate vaccine. Given that the NIS-Teen data also includes youth aged 16 and 17, it is not possible to know whether Pa. is currently meeting the HP2020 goal. However, for this indicator, Pa. did exceed the national average of 85.1% (95% CI: 84.2, 86.0) in 2017 (CDC, NIS-Teen 2015-2017).

Transition to Adult Care: The transition from pediatric to adult-oriented health care often involves various steps including identification of new providers transfer of records and verification of insurance coverage. As such, support may be necessary. As of 2016-2017, 16.2% (95% CI: 12.2, 21.0) of adolescents (aged 12 to 17) reported receiving the services necessary to make the transition to adult health care. Although above the national average (14.6%, 95% CI: 13.7, 15.5), disparities in Pa. exist, as only 5.6% (95% CI: 1.5, 18.5) of black adolescents reported receiving the necessary services for the transition as compared to 16.3% (95% CI: 12.4, 21.1) of white adolescents (DRCCAH, 2016-2017).

Parental Support: Increasing protective factors such as parental support and interaction helps buffer the harmful effects of risks and risk behaviors. The behaviors and relationships within an adolescent's family contribute to that adolescent's risk for harmful behaviors. The HP2020 goal is to increase the proportion of adolescents aged 12 to17 who can speak to a parent or caregiver about a serious problem to 83.2% (ODPHP, 2020). Nationally, the HP2020 data from the National Survey on Drug Use and Health (NSDUH) for this goal has demonstrated a slight increase from 78.2% (95% CI: 77.4,78.9) in 2013 up to 80.1% (95% CI: 79.4, 80.9) in 2016 (ODPHP, 2020). In Pa., the percentage has also increased slightly from 77.2% (95% CI: 75.7, 78.6) of adolescents reporting that they feel able to speak with a parent or caregiver during 2009-2012 and 79.9% (95% CI: 78.1, 81.7) reporting the same during 2013-2016. Although shy of the HP2020 goal, the Pa. percentages for this indicator are similar to the other reporting states for these time periods.

Risk Factors

Physical Inactivity: Pa. has seen an increase from 2009 to 2017 in the percentage of high school-aged adolescents (12 to 17 years old) who were not physically active at least 60 minutes per day on five or more days during the last week (54.1% reported physical inactivity in 2009 via YRBS as compared to 57.6% in 2017). Pa. youth are less physically active than the national average, as, nationally, only 53.5% of adolescents reported less than 60 minutes of physical activity on five or more days during the last week in 2017. In Pa., adolescent females report significantly lower rates of physical activity than male adolescents; in 2017, 67.7% of females reported less than 60 minutes of physical activity per day, while only 47.4% of males reported inadequate physical activity. Pennsylvania Youth Risk Behavior Surveillance System (YRBSS) data from 2017 also show that a larger percentage racial and ethnic minority youth (from 62.3% among black/African American youth up to 70.7% of Asian youth), as well as sexual minority youth (gay, lesbian or bisexual 77.2%; bisexual 80%), report more physical inactivity as compared to their white (54.9%) and/or heterosexual classmates (54.9%) [CDC, YRBSS, 2009, 2015, 2017].

Condom/Contraception Use: The percentage of high school-aged adolescents in Pa. who reported not using both a condom and other form of contraception (IUD or hormonal) at last intercourse has decreased from 91.9% (95% CI: 88.4, 94.4) in 2015 to 86.8% (95% CI: 83.5, 89.5) in 2017. While this decrease suggests that use of both a condom and hormonal contraception may be increasingly common among heterosexual adolescents in Pa., two years of data are not sufficient to understand the pattern. As such, continued characterization of condom and IUD or hormonal contraception use among adolescents is merited; even as IUDs and other contraception methods become more accessible to youth, condom use must be emphasized as well to prevent the transmission of STDs/STIs (CDC, YRBSS, 2015, 2017).

Interpersonal Violence/Bullying: Among high-school aged students, Pa. YRBS 2017 data indicates that male students report being involved in a physical fight at a higher percentage (28.9%, 95% CI: 26.2, 31.8) than their female classmates (16.4%, 95% CI: 13.1, 20.2). It also appears that fights occur (or are reported) more often at a younger age, as 29.7% (95% CI: 24.9, 34.9) of youth in ninth grade report a fight within the last 12 months, while only 18.4% (95% CI: 14.5, 23.1) of youth in twelfth grade report a fight within the last 12 months. Pa. is surpassing the HP2020 goal of reducing reports of physical fighting in the last twelve months to only 28.4% (Pa. is currently at 22.8%, 95% CI: 20.5, 25.4) of youth reporting physical fights) and has been consistently below the national average from 2009 to 2017 (ODPHP, 2020; CDC, YRBSS, 2009, 2015, 2017).

In 2017, Pa. YRBS included a new survey question regarding sexual violence. In Pa., 10.1% (95% CI: 8.7, 11.6) of adolescents reported experiencing sexual violence as compared to 9.7% (95% CI: 9.0, 10.5) nationally. When stratified by sexual orientation, YRBS data demonstrated that reports of experiencing sexual violence were more common among gay, lesbian or bisexual youth in Pa. as compared to their heterosexual classmates; 20.5% (95% CI: 15.3, 27.0) of gay, lesbian or bisexual youth reported experiencing sexual violence in 2017 as compared to 8.7% (95% CI: 7.3, 10.3) of heterosexual youth (CDC, YRBSS, 2017).

According to Pa. YRBS data, student reports of bullying on high school property in Pa. have increased by nearly 3% from 2009 to 2017 (19.2%, 95% CI: 16.9, 21.8) to 21.7%, 95% CI: 19.3, 24.3) and the percentage of students who reported bullying was nearly twice as high among gay, lesbian or bisexual youth in 2017 (41.6%, 95% CI: 32.3, 51.6 of bisexual youth and 40.3%, 95% CI: 33.1, 48.0 of gay, lesbian or bisexual youth reported experiencing bullying at school as compared to 19.6%, 95% CI: 17.3, 22.2 of heterosexual youth reporting bullying). Although on average, Pa. reports of bullying by students in grades nine through 12 are similar to the national average (19.0%, 95% CI: 17.6, 20.5 of high school students reported bullying nationally in 2017), Pa. has not achieved the HP2020 goal of only 17.9% of adolescents reporting bullying at school (ODPHP, 2020; CDC, YRBSS, 2009, 2015, 2017).

Given the increasing role of social media and the internet in the lives of adolescents, bullying via electronic means of communication is also commonplace and, like in-school bullying, may have a negative impact on the social and emotional well-being of youth. In Pa., reports of electronic bullying among adolescents increased from 14.4% (95% CI: 12.4, 16.4) in 2015 to 17.3% (95% CI: 15.6, 19.1) in 2017, and stratified data indicates significantly higher percentages of lesbian, gay, or bisexual students (32.1%, 95% CI: 25.0, 40.2) who report experiencing bullying electronically as compared to 15.8% (95% CI: 14.3, 17.5) of heterosexual students reporting electronic bullying. Females in Pa. are also reporting more electronic bullying (23.5%, 95% CI: 20.9, 26.4) than their male classmates (11.3%, 95% CI: 9.5, 13.3) [CDC, YRBSS, 2009, 2015, 2017].

Smoking and Alcohol Consumption: The percentage of adolescents in Pa. who reported smoking tobacco cigarettes within the last 30 days has dropped from 18.4% (95% CI: 15.1, 22.3) in 2009 to 8.7% (95% CI: 7.5, 10.2) in 2017. This appears to be the trend nationally as well (19.5%, 95% CI: 17.9, 21.2 in 2009 to 8.8%, 95% CI: 7.2, 10.7 in 2017). While this trend is encouraging, the use of e-cigarettes and vaping among teens has been on the rise according to numerous reports. 2017 YRBS data shows 41.8% (95% CI: 39.1, 44.5) of Pa. teens have tried e-cigarettes, and 11.3% (95% CI: 9.3, 13.7) currently use e-cigarettes. In comparison, as of 2017, 28% (95% CI: 25.5, 30.6) of youth reported having tried smoking tobacco cigarettes, and 8.7% (95% CI: 7.5, 10.2) currently smoke tobacco cigarettes. Stratified 2017 Pa. YRBS data shows smoking cigarettes increases with age and remains common among gay, lesbian or bisexual youth in Pa. Approximately 20% (95% CI: 14.7, 26.5) of gay, lesbian or bisexual youth report smoking as compared to only 7.8% (95% CI: 6.6, 9.2) of heterosexual youth who report smoking (CDC, YRBSS, 2009, 2015, 2017).

As of 2017, the percentage of Pa. adolescents who consume alcohol increases with age (20.7%, 95% CI: 16.7, 25.2 in ninth grade, vs. 41.4%, 95% CI: 36.3, 46.7 in twelfth grade), with consumption most commonly reported among females (33.7%, 95% CI: 30.7, 36.9) and gay, lesbian or bisexual youth (39.6%, 95% CI: 31.5, 48.3) as compared to males (28.6%, 95% CI: 25.3, 32.1) and heterosexual youth (30.7%, 95% CI: 28.3, 33.3), respectively. The percentage of high school-aged adolescents who report consuming alcohol has decreased from 2009 (38.4%, 95% CI: 34.2, 42.8) to 2017 (31.1%, 95% CI: 28.5, 33.7) and is similar to the national average (29.8% of adolescents reporting alcohol consumption nationally). The HP2020 goal for alcohol consumption is specific to high school seniors and aims to increase the number of seniors who have never consumed alcoholic beverages (ODPHP, 2020). 2017 YRBS results from Pa. show that 72% (95% CI: 66.2, 77.1) of high school seniors report that they have ever drunk alcohol. As such, it is improbable that Pa. is meeting the HP2020 goal of reducing the percentage of high school seniors never using alcohol to 30.5% (CDC, YRBSS 2009, 2015, 2017).

Inappropriate Use of Prescription Drugs: As inappropriate use of prescription medication is a contributor in the growing opioid epidemic, it is important to understand these trends in the adolescent population. The Pennsylvania Youth Survey (PAYS) is a survey administered to youth in middle school and high school that captures drug use and behaviors. While the trend is small, PAYS data suggest that the percentage of adolescents responding that they have not used prescription pain relievers (zero occasions of use) has slightly increased from 2013 to 2017. Of those reporting having used prescription pain relievers without a doctor's orders in their lifetime, the majority reported using on one to two occasions or three to five occasions. When examined by age group, 11-year-old, 13-year-old, 15-year-old, and 17-year-old youth, each represented approximately 18% of those responding never having used prescription pain relievers without a doctor's orders (zero occasions of use). Youth aged 17 consistently represented the highest percentage of respondents in each of the remaining occasion categories (one to 40 or more occasions). This suggests that inappropriate use of prescription drug use may increase with age.

In 2017, white youth more frequently reported having used prescription pain relievers without a prescription on one to two occasions (82.1%) as compared to youth who identified as non-white (17.9%). White youth were consistently more likely to report one or more (up to 40) occasions of use as compared to non-white youth. Male youth more frequently reported having used prescription pain relievers on three to five occasions without a prescription (53.6%) as compared to female youth (46.4%). Male youth were consistently more likely to report three or more (up to 40) occasions of use as compared to female youth. As a result of the way the data is presented, it is difficult to see any disparities that may exist. Overall, a large majority of adolescents in the PAYS are not using prescription pain relievers without a doctor's orders (Bach Harrison, LLC, Pennsylvania State University [PSU], PAYS 2013-2017).

Adolescent Pregnancy: Pa.'s pregnancy rate among adolescents aged 15 to 17 years old has consistently decreased from 17.4 pregnancies per 1,000 females (95% CI: 16.8, 17.9) in 2012 to 10.6 per 1,000 females (95% CI: 10.1, 11.0) as of 2016, which is well below the national HP2020 goal of 36.2 (ODPHP, 2020). When stratified by race, the rates range from 2.8 (95% CI: 1.7, 4.0) among Asian/Pacific Islander female adolescents to a high of 25.4 (95% CI: 23.7, 27.1) among black/African American female adolescents and are still below the HP2020 goal. Regionally, there are five counties (Berks, 15.6; Fayette, 16.1; Lehigh,13.4; Luzerne, 13.4; and Philadelphia, 26.6) with higher rates of pregnancy among adolescents as compared to the state rate (DOH, Birth Certificate Data, 2012-2016).

Morbidities

Non-fatal Injury Hospitalization: Non-fatal injury hospitalization rates among adolescents aged 10 to 19 have decreased in Pa. from 388.8 hospitalizations per 100,000 adolescents in 2011 to 311.1 hospitalizations per 100,000 adolescents in 2014. Following the transition from ICD-9 to ICD-10 codes, recent PHC4 data from 2016 indicate that the non-fatal injury hospitalization rate in Pa. among adolescents aged 10 to 19 may be as low as 266.9 hospitalizations per 100,000 adolescents (PHC4, 2019). However, the Pa. rate is still higher than the national rate as of 2016, which was 216.4 hospitalizations per 100,000 (U.S. DHHS, 2017).

Depression/Suicide-related Behaviors: The percent of adolescents who report feeling sad or hopeless is on the rise. In Pa., the percentage of adolescents reporting sadness/hopelessness increased from 23.5% (95% CI: 20.8, 26.5) in 2009 to 29.4% (95% CI: 27.3, 31.5) in 2017. However, Pa.’s percentage of adolescents reporting sadness/hopelessness is slightly lower than the national average of 31.5% (95% CI: 29.6, 33.4) in 2017. In 2017, a higher percentage of female students reported feeling this way (38.6%, 95% CI: 35.3, 42.0) as compared to male students (20.4%, 95% CI: 18.3, 22.7). Gay, lesbian or bisexual youth were more than twice as likely to report feeling sad or hopeless compared to their heterosexual classmates (25.8%, 95% CI: 23.9, 27.8). Hispanic/Latino (35.2%, 95% CI: 31.5, 39.1) and multiple race students (36.4%, 95% CI: 29.2, 44.2) were also more likely to express feelings of sadness or hopelessness as compared to white students (28.2%, 95% CI: 25.8, 30.8) [CDC, YRBSS, 2009, 2015, 2017].

Pa.'s percentage of adolescents who report suicidal ideation within the last year was consistently slightly lower than the national average from 2009 to 2017 (15.1%, 95% CI: 13.5, 16.8 in Pa. as of 2017; 17.2%, 95% CI: 16.2, 18.3 nationally). Female adolescents (20.6%, 95% CI: 18.4, 23.1) were more likely to report suicidal ideation as compared to male adolescents (9.7%, 95% CI: 7.7, 12.3) and gay, lesbian or bisexual youth reported the highest percentages of suicidal ideation as compared to heterosexual students (28.6%, 95% CI: 17.6, 42.8 among gay or lesbian students and 41.4%, 95% CI: 31.3, 52.3 among bisexual students as compared to 12.1%, 95% CI: 10.5, 13.9 among heterosexual students) [CDC, YRBSS, 2009, 2015, 2017].

Obesity: Childhood obesity is on the rise and may result in serious health implications later in life. As of 2016-2017, 16.8% (95% CI: 13.2, 21.2) of adolescents aged 10 to 17 in Pa. were reported as obese via the NSCH (BMI at or above the 95th percentile), a percentage that is slightly higher than the national average of 15.8% (95% CI: 14.8, 16.8). Hispanic adolescents had the lowest percentage of obesity at 10.2% (95% CI: 3.7, 30.9) as compared to black/African American adolescents who had the highest percentage of obesity at 23.7% (95% CI: 0.9, 19.3). Additionally, CSHCN were more likely to be obese (28.4%, 95% CI: 19.6, 39.3) as compared to children without special health care needs (13.1%, 95% CI: 9.6, 17.7) [DRCCAH, 2016-2017].

Mortality

Adolescent Mortality: After a decline in mortality rate in Pa. among adolescents aged 10 to 14 from 11.8 deaths per 100,000 (95% CI: 9.4, 14.2) in 2012 to 9.9 deaths per 100,000 (95% CI: 7.7, 12.1) in 2014, the rate increased in 2016 to14.2 deaths per 100,000 (95% CI: 11.5, 16.9). This rate is still below the HP2020 goal of 14.8 deaths per 100,000 adolescents aged 10 to 14 (ODPHP, 2020). Similarly, the 2016 mortality rate among adolescents aged 15 to 19 in 2016 was 47.3 per 100,000 (95% CI: 42.6, 52.0), which is lower than the HP2020 goal of 54.3. Overall, Pa. has met or exceeded the HP2020 goal for both measures since 2012. However, based on 2016 data, disparities exist in both age groups. As of 2016, in the 10 to 14 age group, the mortality rates for black/African American males (33.1, 95% CI: 17.8, 48.3) and white males (16.4, 95% CI: 11.8, 20.9) were elevated and the data for the 15 to 19 age group also shows consistently higher mortality rates for black/African American (118.8, 95% CI: 91.4, 146.2), white (55.9, 95% CI: 47.8, 64.0), and Hispanic males (45.5, 95% CI: 25.0, 65.9) [DOH, Death Certificate Data, 2012-2016].

The 2017 Child Death Review Report indicates that motor vehicles and associated crashes were one of the leading causes of death among reviewed deaths of children aged 15 to 21 in Pa. in 2014. The motor vehicle mortality rate in Pennsylvania among adolescents aged 15 to 19 has decreased since 2012 (12.3 per 100,000); as of 2016, the rate was 10.1 deaths per 100,000 adolescents and males had higher rates of motor vehicle deaths (12.4 per 100,000) than females (7.7 per 100,000). Nationally, the HP2020 target is to reduce the motor vehicle mortality rate for people of all ages to 12.4 per 100,000 (ODPHP, 2020). Among adolescents, Pa. has met or outperformed that goal from 2012 to 2016. Race and county-level data were suppressed for this indicator due to low numbers (DOH, Death Certificate Data, 2012-2016).

Suicide is another leading cause of death among adolescents. Pa.'s suicide rate among adolescents aged 15 to 19 as of 2016 is 9.5 deaths per 100,000 (95% CI: 7.4, 11.6) – an increase from 2012 when the rate was 6.7 deaths per 100,000 (95% CI: 5.0, 8.4). Although Pa.'s adolescent suicide rate is below the HP2020 national target of 10.2 suicides per 100,000, the rate among males in this age group is 14.3 deaths per 100,000 (95% CI: 10.7, 17.9), which is more than three times the rate among females (4.5 per 100,000, 95% CI: 2.4, 6.5) [ODPHP, 2020; DOH, Death Certificate Data, 2012-2016].

Health of Children and Youth with Special Health Care Needs

Population Demographics

Children with special health care needs (CSHCN) are children ages 1 to 21 who have or are at increased risk for a chronic condition and who also require health care and related services of a type or amount beyond what is required by children generally (U.S. DHHS, 2015, Appendix, p. 106). As of 2016, the NSCH indicated that 19.3% (95% CI: 16.5, 22.4) of children aged 0 to 17 in Pa. are CSHCN (DRCCAH, 2016-2017).

As of 2016, the NSCH indicated that 7.5% (95% CI: 5.5, 10.2) of children aged 3 to 17 in Pa. had been diagnosed with Attention Deficit Disorder (ADD) or Attention-Deficit/Hyperactivity Disorder (ADD/ADHD) [DRCCAH, 2016-2017].

As of 2016, the NSCH indicated that 2.2% (95% CI: 1.3, 3.9) of children aged 3 to 17 in Pa. had been diagnosed with an autism spectrum disorder (DRCCAH, 2016-2017).

Wellness and Access to Health Care

Access to Coordinated Care/Well-Functioning System: As of 2016-2017, 16.5% (95% CI: 12.3, 21.9) of CSHCN aged 0 to 17 received health care in a well-functioning system in Pa. Although this percentage is higher than the national average of 15.7% (95% CI: 14.5, 16.9) of CSHCN receiving care in a well-functioning system, children without special health care needs in Pa. are still more likely to be receiving care in a well-functioning system (23.3%, 95% CI: 19.9, 27.1). Additionally, Pa. has not yet met the HP2020 goals of increasing the percentage of CSHCN who receive care in a well-functioning system to 22.4% among children aged 0 to 11 and to 15.1% among children aged 12 to 17 (ODPHP, 2020; DRCCAH, 2016-2017).

Medical Home: As of 2016-2017, 45.9% (95% CI: 38.3, 53.6) of CSHCN aged 0 to 17 report receiving coordinated, ongoing, comprehensive care within a medical home in Pa. via NSCH, whereas approximately 49.2% (95% CI: 44.8, 53.5) of children in Pa. without special health care needs report having a medical home Although the percentage of CSHCN in Pa. with a medical home is above the national average of 43.2%, it is below the HP2020 goal of 51.8% for CSHCN (ODPHP, 2020; DRCCAH, 2016-2017).

Behavioral Treatment/Counseling: As of 2016-2017, 4.5% (95% CI: 3.0, 6.6) of children aged 3 to 17 years with ADHD reported receiving needed behavioral treatment within the last 12 months, a percentage that is slightly higher than the national average of 3.9% (95% CI: 3.6, 4.3) [DRCCAH, 2016-2017].

Transition to Adult Health Care: As of 2016-2017, 15.8% (95% CI: 9.2, 25.7) of adolescents (aged 12 to 17) with special health care needs reported receiving the services necessary to make the transition to adult health care in Pa., whereas 16.7% (95% CI: 15.1, 18.5) of adolescents with special health care needs nationwide report receiving such services. Most demographic data were suppressed due to low numbers and to maintain confidentiality, making it impossible to examine stratified data for this indicator (DRCCAH, 2016-2017).

Self-reported Health: Self-reported health is considered a strong indicator of wellness and quality of life. As of 2016-2017, 92.3% (95% CI: 89.7, 94.3) of children aged 0 through 17 were reported to have excellent or very good health via the Pa. NSCH, whereas only 89.8% (95% CI: 89.1, 90.4) of children were reported to have excellent or very good health nationally. Children with special health care needs in Pa. were less likely to be reported as having very good or excellent health in 2016-2017, with only 75.9% (95% CI: 67.9, 82.5) reporting such a health status as compared to 96.2% (95% CI: 93.6, 97.8) among children without special health care needs (DRCCAH, 2016-2017).

Physical Activity: Regular physical activity among children can result in increased likelihood of positive health outcomes across the life course. As of 2016-2017, 28.8% (95% CI: 22.8, 35.7) of children aged 6 to 11 years reported engaging in at least 60 minutes of physical activity everyday via the Pa. NSCH. Similarly, 27.9% (95% CI: 26.5, 29.4) of children aged 6 to 11 reported engaging in daily physical activity nationally. CSHCN (17.6%, 95% CI: 12.6, 24.1) in Pa. were least likely to report participating in 60 minutes of physical activity daily as compared to children without special health care needs (26.7%, 95% CI: 21.9, 32.2) [DRCCAH, 2016-2017].

Risk Factors

Inadequate Access to Needed Care: As of 2016-2017 6.5% (95% CI: 2.8, 14.1) of CSHCN aged 0 to 17 reported not receiving needed health care in Pa. Although this percentage is lower than the national average (8.1%, 95% CI: 6.8, 9.6), it is still higher than the percentage reported by children without special health care needs; in 2016-2017, only 1.0% (95% CI: 0.3, 3.0) of children in Pa. without special health care needs reported not receiving needed health care (DRCCAH, 2016-2017).

Inadequate Health Insurance: The NSCH characterizes "adequacy" of health insurance by assessing whether the child's health insurance covers needed services and providers and reasonably covers costs. As of 2016-2017, 77.9% (95% CI: 74.7, 80.8) of children aged 0 to 17 were reported as having adequate health insurance in Pa., whereas only 74.4% (95% CI: 73.6, 75.1) had adequate health insurance nationally. CSHCN were less likely to have "adequate" health insurance in Pa. (68.6%, 95% CI: 60.5, 75.7) as compared to children without special health care needs (80.2%, 95% CI: 76.8, 83.2) [DRCCAH, 2016-2017].

Adverse Childhood Experiences (ACEs): Adverse childhood experiences (ACEs) are events that cause stress or trauma in a child's life and may impact health outcomes and well-being across the life course. The NSCH asks parents whether their child has experienced one of the following ACEs: 1) parent or guardian divorce or separation; 2) death of parent or guardian; 3) jail time for parent or guardian; 4) witnessed/heard violence between parents; 5) victim or witness of neighborhood violence; 6) lived with someone with mental illness; 7) lived with anyone with a drug/alcohol problem; 8) unfair treatment/judgement because or race/ethnicity; and 9) hard to get by on family's income. As of 2016-2017, 24% (95% CI: 20.8, 27.6) of children aged 0 to 17 had experienced at least one ACE and 19.2% (95% CI: 16.4, 22.4) had experienced two or more in Pa. Nationally, the percentage of children who have experienced an ACE is comparable (24.6%, 95% CI: 23.8, 25.4). There was a higher percentage of CSHCN who had experienced two or more ACEs (33%, 95% CI: 26.1, 40.7) as compared to children without special health care needs (15.9%, 95% CI: 12.9, 19.4) in Pa. (DRCCAH, 2016-2017).

Bullying: According to 2016-2017 NSCH data, 19.0% (95% CI: 15.9, 22.5) of children aged 6 to 17 were reported as having experienced bullying in Pa., a percentage that is slightly below the national average of 21.7% (95% CI: 20.9, 22.5). A higher percentage of CSHCN were bullied (34.1%, 95% CI: 27.0, 42.0) as compared to children without special health care needs (14.2%, 95% CI: 10.9, 18.2) in Pa. (DRCCAH, 2016-2017).

Morbidity

Tooth Decay: Tooth decay is a preventable condition that is common among children. As of 2016-2017, 12.0% (95% CI: 9.4, 15.2) of children aged 0 to 17 reported having had tooth decay or a cavity in the past year via the PA NSCH – a percentage that is only slightly above the national average (11.7%, 95% CI: 11.1, 12.4). In Pa., tooth decay was also more common among CSHCN (17.5%, 95% CI: 11.5, 25.9) than among children without special health care needs (10.6%, 95% CI: 7.8, 14.2) [DRCCAH, 2016-2017].

Obesity: Childhood obesity is on the rise and may result in serious health implications later in life. As of 2016-2017, 16.8% (95% CI: 13.2, 21.2) of adolescents aged 10 to 17 in Pa. were reported as obese via the NSCH (BMI at or above the 95th percentile), a percentage that is slightly higher than the national average of 15.8% (95% CI: 14.8, 16.8). CSHCN in Pa. were more likely to be obese (28.4%, 95% CI: 19.6, 39.3) as compared to children without special health care needs (13.1%, 95% CI: 9.6, 17.7) [DRCCAH, 2016-2017].

Mortality

Death Attributed to Birth Defects: Pa. aims to reduce the rate of infant deaths due to birth defects. The HP2020 goal is to reduce the rate of infant deaths due to birth defects to 1.30 deaths per 1,000 live births (ODPHP, 2020). The national rate for this measure has met the HP2020 goal in each of the last five years from 2012 to 2016 (1.22 deaths per 1,000 live births in 2016) [ODPHP, 2020]. In each year, Pa. has met the HP2020 goal and been lower than the national rate (1.0 deaths per 1,000 live births in 2016). Pa. has reached this goal every year of the five-year period (2012-2016), reducing the rate of deaths due to birth defects for the five-year period from 1.20 deaths per 1,000 live births in 2012 to 1.00 deaths per 1,000 live births in 2016. As of 2016, the death rate attributed to birth defects in Pa. was highest among infants born to mothers with low educational attainment (high school degree or below) [CDC, CDC Wonder 2012-2016].

Primary Data Collection

Web Survey: Social Determinants of Health

In addition to analyzing existing health data on MCH populations, seeking input from families and their providers was an important part of the Title V Five-Year Needs and Capacity Assessment. From May 30, 2019, to June 28, 2019, the BFH requested input from Title V service recipients and providers on their experiences with the care system and factors influencing their health via a web survey. The survey was distributed in both English and Spanish through provider email distribution lists and via the department’s Facebook and Twitter pages. Existing Title V partners, vendors and collaborators were asked to disseminate the link to the survey(s) to service recipients and families that they served via email. If providers determined that the patients and families that they served would be more likely to complete a paper survey, a PDF of the survey was provided so that it could be printed, distributed and returned via mail to the BFH.

There were 554 respondents to the web survey, 172 of whom were recipients of health services and 382 of whom were Title V service providers or their partners. Approximately 3% of respondents completed the survey in Spanish and 4.2% of respondents submitted paper surveys. Service recipients resided in 41 of the 67 counties in Pa. The response to this web survey was one of the most robust that the BFH has witnessed to date – potentially indicative of successful survey distribution and strong interest in the outcome of the assessment.

Given that the survey was not representative of all of Pa. and was the result of a convenience sample, the results should be interpreted with caution. The BFH considered the web survey a pilot aimed at exploring social determinants of health, and the results were primarily utilized to inform subsequent discussions with stakeholders through focus groups or in-person prioritization events, both of which are discussed in greater detail in this report.

Focus Groups

During the months of July and August 2019, the BFH engaged providers and service recipients in focus group discussions to gather additional, in-depth information on factors influencing health within families across Pa. Seven focus groups were held across the state in the different community health districts in order to get broad geographic representation. The BFH's goal was to hold at least two focus groups per Title V population domain – one engaging health professionals providing services to that population domain and a second engaging service recipients. In total, 88 people across the state were engaged in focus group discussions about social determinants of health. BFH staff facilitated the focus groups using a standardized facilitation guide, which is included in the Appendix (Supplement D). Some of the prompts in the facilitation guide aimed to get additional information/insight on themes or issues that had become apparent in the web survey. The BFH sought partners who would host each focus group, advertise the opportunity to their staff and/or service recipients and families in their network of care, and provide reimbursement to service recipient focus group participants as needed for travel to and from the event. Examples of the flyers utilized to advertise these focus groups are included in the Appendix (Supplement E). Focus groups were held at the following locations:

Child and Adolescent Health: Providers and Service Recipients

- Maternal and Family Health Services Family Planning Center, Wilkes-Barre, Pa.: July 10, 2019
- Bradbury Sullivan LGBT Center, Allentown, Pa.: July 31, 2019

Health of CSHCN: Providers and Service Recipients

- Pennsylvania Training and Technical Assistance Network (PaTTAN) Transition Conference, State College, Pa. July 17, 2019
- Children's Hospital of Philadelphia (CHOP) and Leadership Education in Neurodevelopmental Disabilities Fellows (LEND), Philadelphia, Pa.: July 29, 2019
- Parent Education, Advocacy, and Leadership Center (PEAL), Pittsburgh, Pa.: July 31, 2019

Women/Maternal Health and Infant/Perinatal Health: Providers and Service Recipients

- Black Women's Health Association, Philadelphia, Pa.: July 30, 2019
- Healthy Start, Pittsburgh, Pa.: August 14, 2019

At the start of each focus group, participants were asked to complete an audio recording consent form and a short form survey to get a sense of their demographics and personal characteristics (Supplement F). The short form survey was anonymous, and participants were asked not to include any personal information in their responses. Of the 88 service recipients engaged in focus group discussions, the participants identified as female (84.1%), male (11.4%) or as genderfluid or transgender (4.5%). Most of the participants identified as white (61.9%) or black/African American (32.1%), while others identified as Hispanic/Latino (4.8%) or Asian (1.2%).

Anonymized results from the focus group discussions were summarized, and the themes that emerged consistently across focus group discussions were identified using qualitative analysis. Women, mothers and their providers described the following common themes:

- (1) Health services should be accessible;
- (2) Support and services during and after pregnancy are important;
- (3) Experiences with economic instability negatively impact health;
- (4) Experiences with discrimination are common and discrimination occurs while seeking health care;
- (5) Women do not feel heard or taken seriously in health-related decision-making; and
- (6) Lack of or inadequate health insurance impacts access to health care.

Adolescents, youth and their providers described the following common themes:

- (1) Youth do not feel heard or taken seriously in health-related decision-making;
- (2) Needed health services are inaccessible due to transportation barriers;
- (3) Mental and behavioral health services are important;
- (4) Lack of access to basic resources and housing negatively affects health;
- (5) Lack of access to health insurance and fear of medical expenses limit use of the health care system by youth; and
- (6) Culturally competent and sensitive care is important.

Children and youth with special health care needs, their families and their providers described the following common themes:

- High rates of doctor turnover, support staff turnover and the lack of continuity of care negatively affects CSHCN health;
- (2) Experiences with discrimination are common and discrimination occurs while seeking health care;
- (3) High cost of insurance and inadequate insurance impact which needed services CSHCN are able to receive;
- (4) There is a lack of adequate transportation to needed health services;
- (5) Transition from pediatric to adult care is important;
- (6) Caregivers experience high levels of stress and lack of respite impacts their relationships and health; and
- (7) Access to dental services is limited due to lack of dentists/orthodontists willing to see CSHCN.

Development of Data Briefs

At the start of the Title V Five-Year Needs and Capacity Assessment, the BFH committed to engaging MCH stakeholders and keeping them informed of both the assessment’s methods and outcomes throughout the process. As such, following the completion of the data collection and analysis phase of the assessment, the BFH developed a series of data briefs that provide an overview of Title V and the needs and capacity assessment and summarize the results from the analysis of available health data, as well as the feedback received from families, service recipients and providers through the web survey and focus groups.

The final data briefs are included in the Appendix (Supplement G). While the contents of the data briefs are similar to that of an executive summary, the BFH aimed to employ a structure and format that made the document more visually appealing and user-friendly. Additionally, the goal was that each MCH population domain would have a distinct section that, when separate from the other pages, could stand alone. The data briefs were posted on the Title V website, circulated to Title V stakeholders via email and distributed to stakeholders for review at regional prioritization events.

Capacity Assessment: Title V Program Capacity

An important component of the Title V Five-Year Needs and Capacity Assessment is evaluation of the health system's infrastructure and the Title V program's organizational capacity, agency capacity and workforce capacity.

Organizational Structure

The first step in evaluating Pa.'s Title V program's ability to provide comprehensive health services across the life course to MCH populations is to describe the infrastructure of the state's public health system and the organizational structure of the DOH. To some extent, the success of the state's Title V program is dependent on this underlying infrastructure. As such, it provides important context for the assessment of capacity.

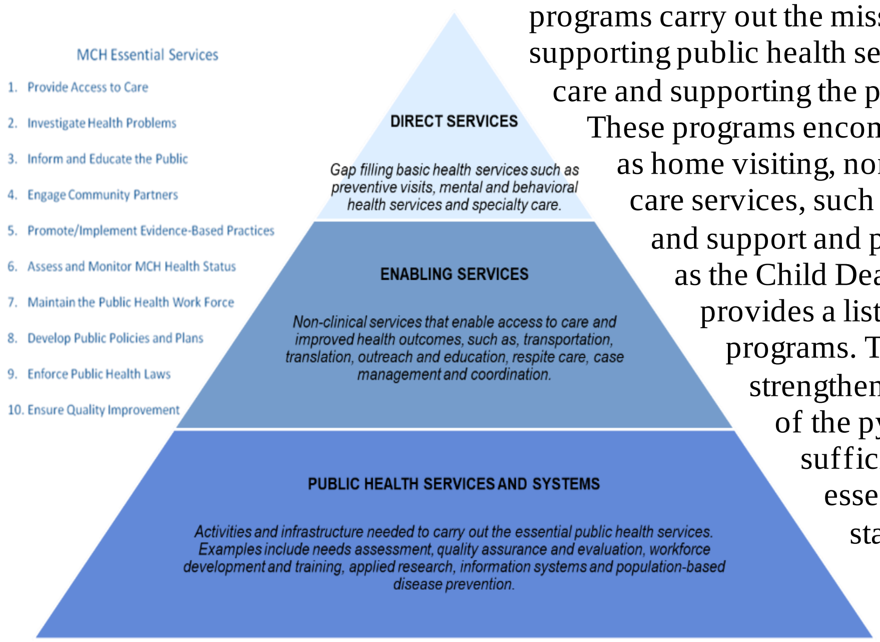
The mission and efforts of the DOH are guided by the commonwealth's leadership. Governor Tom Wolf was inaugurated as the Commonwealth of Pennsylvania's 47th governor on January 20, 2015 and was re-elected for a second term in 2018. The governor's cabinet is comprised of the directors of various state agencies who are appointed by the governor and confirmed by the Pennsylvania Senate. All cabinet members are responsible for advising the governor on subjects related to their respective agencies.

Dr. Rachel Levine was confirmed as secretary of health in March 2018 and serves as a cabinet member. Secretary Levine serves as the chief executive officer for the DOH and sets the policies, direction and mission of the department. Secretary Levine also establishes strategic goals and objectives and advises the governor on all medical and public health-related issues and policies. The mission of the DOH is to promote healthy behaviors, prevent injury and disease, and to assure the safe delivery of quality health care for all people in Pennsylvania.

The DOH's BFH is the State Title V Agency in Pa. and is responsible for administering programming and activities funded by the Title V MCHSBG. The BFH's Divisions of Child and Adult Health Services (CAHS), Community Systems Development and Outreach (CSDO), Newborn Screening and Genetics (NSG) and Bureau Operations (DBO) administer and oversee programming and activities that aim to improve the health and well-being of Pa.'s mothers, women, infants, children and youth, and CSHCN and their families. For additional information regarding the organizational structure of the DOH and the BFH, please see the organizational chart in Supplement H.

At the time that the Needs and Capacity Assessment was conducted, the BFH was operating approximately 30 programs or distinct activities using Title V funds. The BFH also administers other programs using federal grants and state funding. Collectively, these programs carry out the mission of Title V by establishing and supporting public health services and systems, enabling access to care and supporting the provision of gap-filling direct services. These programs encompass direct reimbursable services, such as home visiting, non-reimbursable primary and preventive care services, such as improving breastfeeding awareness, and support and public health services and systems, such as the Child Death Review Program. Supplement I provides a listing of all of the Title V supported programs. The BFH continues to work toward strengthening the public health systems at the base of the pyramid in order to ensure that there is sufficient capacity and infrastructure for the essential MCH services to be delivered statewide.

Figure 1: Maternal and Child Health Pyramid of Health Services and Essential MCH Services

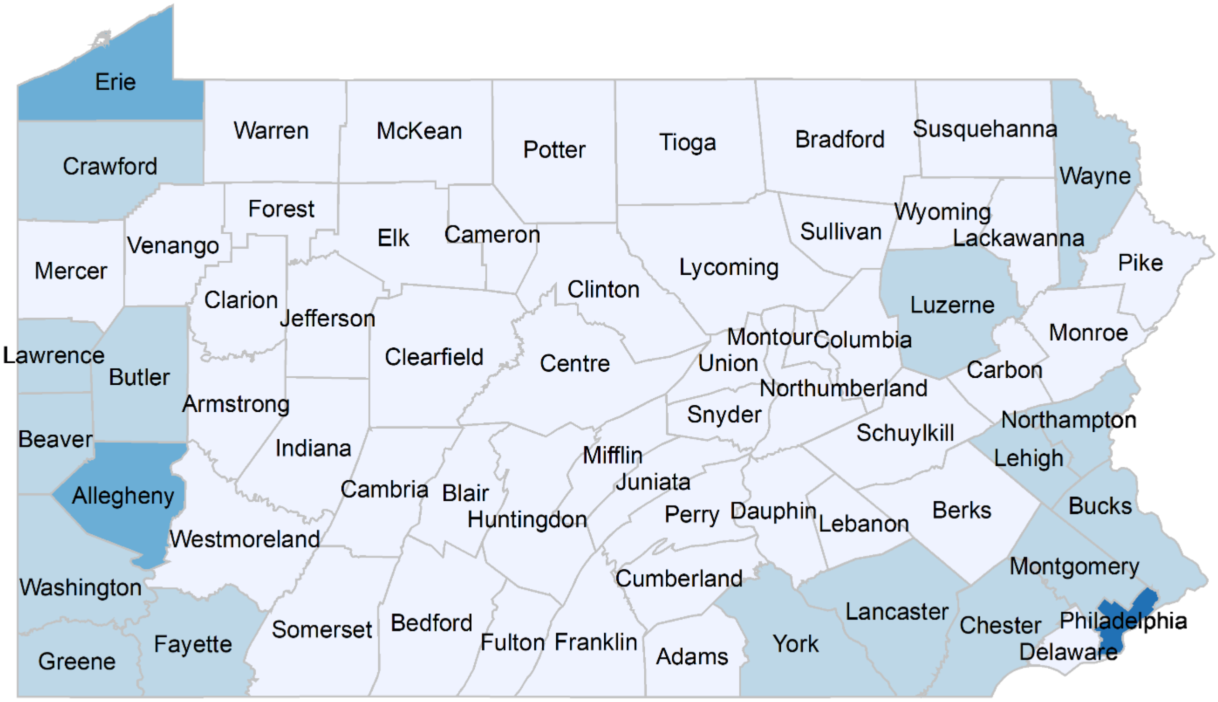


SOURCE: Adapted from Understanding Title V of the Social Security Act, US Department of Health and Human Services, Maternal and Child Health Bureau, 2000.

As part of the Needs and Capacity Assessment, the BFH also evaluated the geographic breadth of Title V programming in Pa. and the breakdown of programming services by the type of service that they provide: direct, enabling or public health services/systems.

The maps pictured in Figures 2, 3 and 4 were developed in ArcGIS based on the Title V programs that the bureau was administering at the time of the Needs and Capacity Assessment. Figure 4 indicates that Title V programming which supports public health systems and services are offered consistently across the state – with 11 to 12 Title V programs offering support in all 67 of Pa.'s counties. While direct and enabling services (Figures 2 and 3, respectively) provided by Title V programs are also present in all 67 counties, counties that have more programming are those located in the most populous corners of the state or that also house a county or municipal health department.

Figure 2: Number of Title V-Supported Programs Offering Direct Services in Pennsylvania by County, 2018

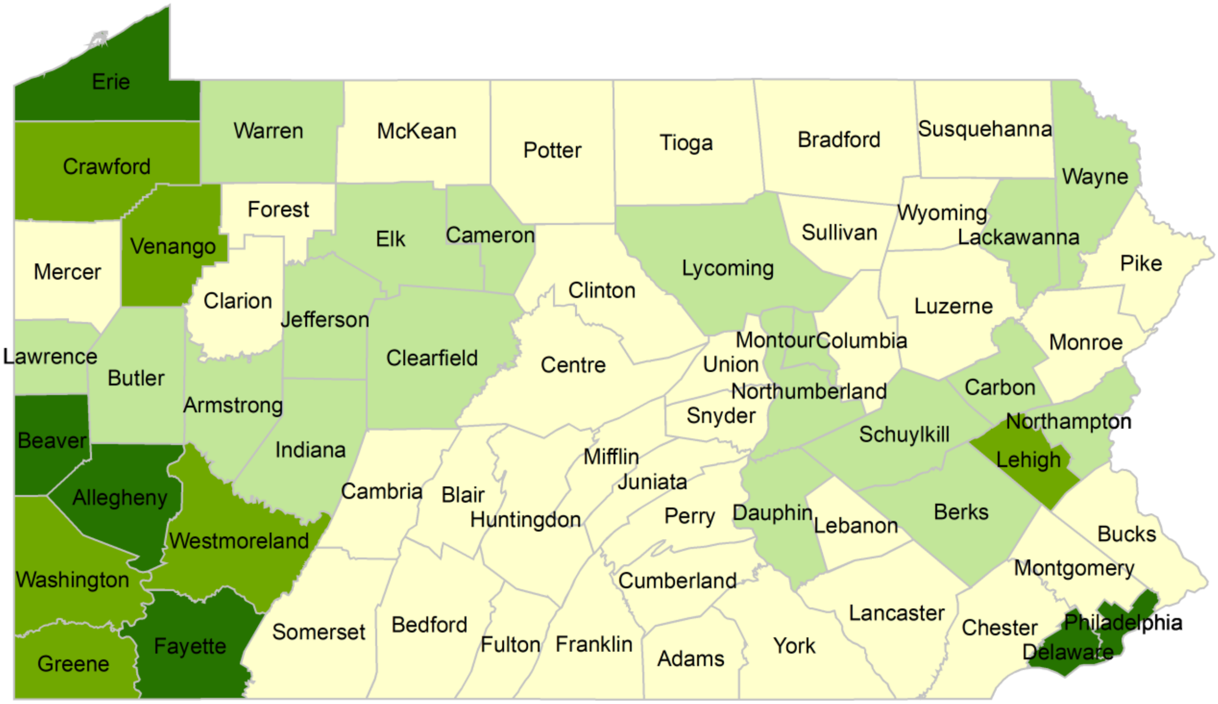


Legend: Number of Programs Offering Direct Services

■ 4
■ 5
■ 6
■ 7

SOURCE: Title V-Supported Programs and Activities, 2018. Department of Health, Bureau of Family Health

Figure 3: Number of Title V-Supported Programs Offering Enabling Services in Pennsylvania by County, 2018

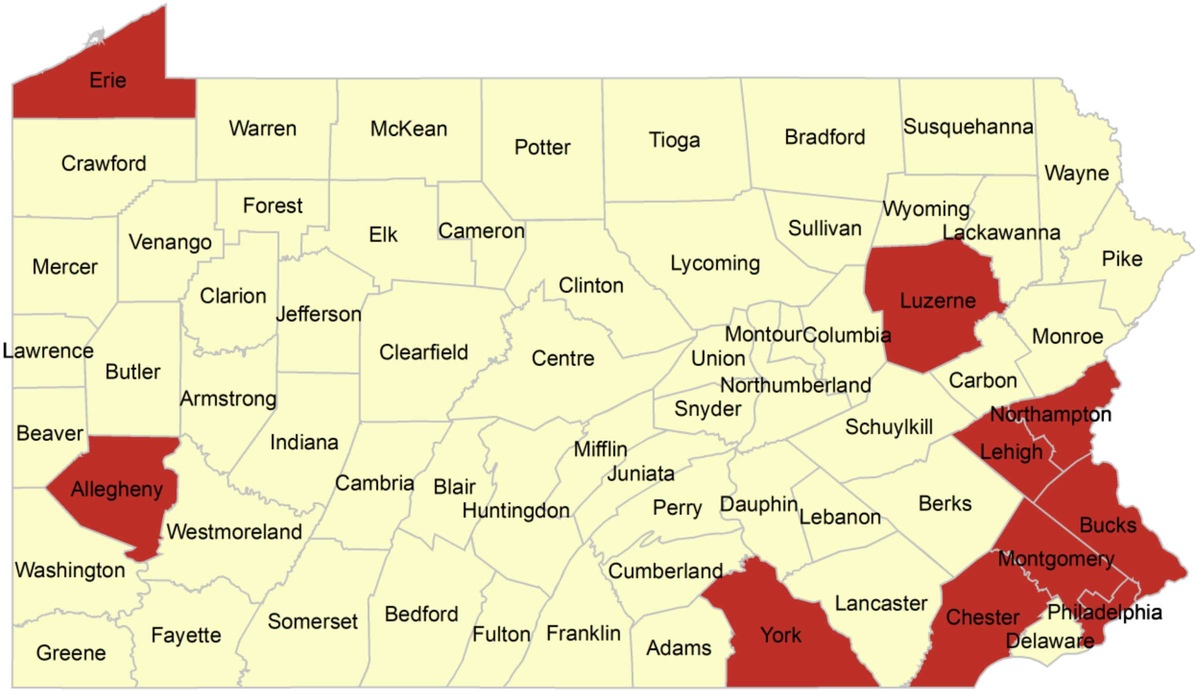


Legend: Number of Programs Offering Enabling Services

🟨 3
🟩 4
🟩 5
🟩 6-8

SOURCE: Title V-Supported Programs and Activities, 2018. Department of Health, Bureau of Family Health

Figure 4: Number of Title V-Supported Programs Offering Population-Level Services in Pennsylvania by County, 2018



Legend: Number of Programs Offering Population-Level Services

🟨 12
🟥 13

SOURCE: Title V-Supported Programs and Activities, 2018. Department of Health, Bureau of Family Health

Agency Capacity to Serve MCH Populati

In order to maintain infrastructure to support essential public health services and systems at the state level, BFH works with local Title V agencies and selects additional community-based partners throughout the state, using approved procurement policies, to provide public health enabling or direct services to the MCH population in their communities. BFH uses population and public health data to target geographical areas for interventions, and then selects qualified grantees for the project. For all grant agreements, BFH staff develop objectives, work statements and budgets, and provide oversight and monitoring of grantee progress toward the stated goals. Through workforce development, technical assistance, and system change initiatives, BFH ensures its staff and partners have the capacity, expertise, and resources needed to design, implement, and evaluate public health programming that is evidence-based, family and community-driven, shaped by an awareness of the social, economic, and environmental determinants of health, and sensitive to the unique needs of the populations served by the BFH. Below is a description of the state's Title V capacity to provide and assure services within each of the Title V population health domains.

Capacity to Serve Women and Mothers

Pennsylvania's Title V program provides a critical safety net for pregnant women and women of childbearing age. In partnership with providers at the local level, the Title V program works to meet the needs of women in the communities in which they reside. Women accessing Title V services are at higher risk for maternal morbidity and mortality due primarily to the impact of social determinants of health, such as socioeconomic conditions, access to health care services, and the availability of transportation. The resources provided by Title V work to lower this risk at the individual, community, and state level by addressing social determinants, reducing racial disparities in health care, and increasing access to quality health care and health education throughout Pennsylvania.

The BFH collaborates with the 10 local health departments to provide home visiting services to women who do not fit the criteria for the traditional home visiting services. Home visiting services provide education and support on health, nutrition, and positive lifestyle changes for women during the prenatal and postpartum period. The BFH is working to expand Centering Pregnancy, a group prenatal care program shown to increase appointment compliance and knowledge of pregnancy and infant health, and, through the Interconception Care (ICC) Project, the BFH is working to expand screening, counseling, and referrals of underserved women for behavioral risk factors during well child visits. In addition, a fourth trimester care model is being piloted to identify high-risk mothers and increase access to patient-centered postpartum care in the one to three weeks following delivery, improving the health and experiences of women in the immediate postpartum period. Each of these programs educates women on healthy behaviors, the importance of birth spacing, and interconception care with the desired outcome of healthier women, infants, children, and families.

Augmenting and supporting these collaborations is the Pregnancy Risk Assessment Monitoring System (PRAMS), a population-based surveillance system designed to identify maternal attitudes, experiences, and behaviors that occur before, during, and after pregnancy via a stratified sample of women delivering a live birth. Pa. has participated in PRAMS since 2007. PRAMS data are used by the BFH and other MCH stakeholders to develop programs and policies to improve maternal and birth outcomes. The PRAMS methodology is designed with the ability to add supplemental questions to collect data on and respond to emerging public health problems, such as the opioid epidemic and Zika, that affect the MCH population.

The BFH has been successful in supporting women and mothers with gap-filling direct and enabling services by supporting home visiting for women who do not meet traditional eligibility criteria, providing interconception care programming and supporting Centering Pregnancy group prenatal care programs. Given that the scope of such services is limited by program capacity and funding, the BFH sees an opportunity to enhance existing strategies and develop system-level strategies addressing maternal health issues in Pa.

Capacity to Serve Infants

Many of the services focused on perinatal/infant health are provided through collaborative work between the BFH and hospitals or midwifery practices, using a combination of state and federal funds. These services seek to promote infant health and well-being beginning at birth. The BFH's Newborn Screening and Follow-up Program (NSFP) performs follow-up services for dried blood spot, hearing, and critical congenital heart defects screenings. The BFH supports dried blood spot newborn screening by paying for the laboratory analysis of the 10 conditions on the mandatory screening panel. Newborns with presumptive positive screening results are referred to treatment center, some of which are contracted with the BFH. Other hospital-based activities include prevention efforts related to shaken baby syndrome and breastfeeding promotion. The Shaken Baby Syndrome Prevention Program provides supplies and guidance to all birthing and children's hospitals in order to ensure that every parent or caregiver of a child born in Pa. receives shaken baby syndrome education. Keystone 10 is an initiative working with birthing facilities on the adoption and implementation of 10 evidence-based steps to baby friendly facilities using education and regional learning collaboratives. The BFH also supports the development and ongoing implementation of an evidence-based, hospital-based model for safe sleep, through increased staff and caregiver education, to increase infant safe sleep practices during all sleep.

In addition to providing support to hospitals, the BFH also administers and supports programming at the community level to ensure that communities and families have the support they need to care for their infants at home. The BFH infant home visiting programs support families by providing health check-ups, screenings, referrals, parenting advice, and guidance, as well as assisting to navigate other programs and services in the community. Mothers who participate in home visiting programs have lower stress levels and increased sensitivity during interactions with their children promoting positive parenting practices and increasing the health and safety of the entire family.

The BFH also operates the Healthy Baby hotline as a mechanism for pregnant and new mothers to access information and resources on insurance coverage, obtaining prenatal care and referrals to local health care providers and breastfeeding professionals. The Breastfeeding Awareness and Support Program similarly provides education and support services to community partners in areas with low breastfeeding rates. Resources are provided to community partners to overcome health disparities in the breastfeeding community based on population served, demographics, and project feasibility and sustainability.

Finally, the BFH receives neonatal abstinence syndrome (NAS) case reporting. The BFH is currently building capacity to move beyond a surveillance approach, develop a long-term follow-up program and ensure that every newborn receives a referral to early intervention for at-risk tracking services and any other appropriate outpatient referral.

The BFH has successfully implemented gap-filling direct services for infants in the form of home visiting for mothers and infants following birth and breastfeeding awareness/education programming. Additionally, Title V funds support the enabling safe sleep program aimed at reducing sleep-related infant death. This support is complemented by systems-level programming, including the newborn screening and genetics program, child death review, and breastfeeding support at the hospital level through Keystone 10. The BFH sees an opportunity to enhance existing strategies to continue to serve high-risk populations and to expand systems-level work.

Capacity to Serve Children

The provision of child health programs by the BFH are community-based. In 2019, 4.4% of children in Pa. were without health insurance coverage and 47% of children were covered by Medicaid or the Children's Health Insurance Program (CHIP). As such, one important component of the state Title V program is to provide for uninsured children in Pa. Title V nurses in the 10 local health departments staff clinics for children who are uninsured, underinsured, or uninsurable. Assessments and basic health services, such as growth and development, lead screenings, and immunizations, are offered as well as referrals for other needed services. Title V nurses also staff dedicated immunization clinics in numerous locations throughout the state to ensure vaccinations are accessible for all families. These services are provided to offer a safety net for the Title V population.

In addition to providing for uninsured children, the BFH supports a variety of child health focused programs to educate families on the importance of well child visits, child development, and nutrition. The Philadelphia Department of Public Health offers a clinic specifically designed for youth aimed toward improving their health and knowledge about health-related issues. Staff assesses psychosocial and reproductive needs and offers referrals to clinical, social, and behavioral health services, as well as engaging teens in reproductive life planning. Additionally, various school-based programs targeting children's self-esteem, positive body image, and goal setting have been implemented.

The BFH also aims to promote and improve the health and safety of families and homes in Pennsylvania. By leveraging resources and working collaboratively with local partners, BFH's programs aim to educate families on childhood lead poisoning prevention, lead hazards, and what makes a healthy home. This is achieved by assessing and addressing health and safety hazards to reduce injury, remediating problems identified as toxic, providing intervention and case management for children with elevated blood lead levels, and advocating for families to have healthier living conditions. Furthermore, the DOH tracks and monitors childhood lead activity through the Pennsylvania National Electronic Disease Surveillance System (PA-NEDSS). PA-NEDSS is a web-based application system that receives all lead reports on Pennsylvania's children. The BFH utilizes available data through PA-NEDSS to identify possible high-risk areas, locate areas of undertesting and identify other potential service gaps.

The BFH administers the Public Health Child Death Review (CDR) Program, which requires local multiagency, multidisciplinary child death review teams to examine the circumstances surrounding the deaths of all children 21 years of age and under residing in the county, for the purpose of identifying risk factors and promoting safety of children to reduce child fatalities. Based on these reviews, local CDR teams make prevention recommendations to local agencies, the state CDR team and the DOH. Each county in the commonwealth is statutorily required to have a team or participate on a regionally based team with another county or counties.

The BFH currently supports the enabling safe and healthy homes program aimed at reducing health risks and hazards in children's homes, supports gap-filling direct services provided to children by county and municipal health departments and supports the system-level CDR teams which operate statewide. In addition to enhancing the existing capacity of CDR teams, the BFH sees an opportunity to address behavioral, mental and developmental health needs among children and to develop systems-level strategies addressing trauma.

Capacity to Serve Adolescents

The BFH aims to serve Pennsylvania's adolescents through a number of partnerships and initiatives, with a particular focus on youth in high-need areas of the commonwealth. Title V and other federally funded adolescent programs range from teen pregnancy prevention and sexual health education to bullying prevention, mentoring, and services for lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth.

Personal Responsibility Education Program (PREP) and Sexual Risk Avoidance Education (SRAE) funding supports programs to delay sexual activity, increase condom or contraceptive use, and reduce pregnancy. Evidence-based programs are implemented in community-based organizations, schools, and other youth-serving agencies. Health Resource Centers (HRCs) operate in high-need areas of the commonwealth, where teen pregnancy rates, sexually transmitted infection (STI) rates, and school drop-out rates are higher than the state average. HRCs provide sexual health education, counseling, and referrals to youth in schools or other easily accessible locations. The BFH also supports Title X clinics by supplementing services for youth 21 years of age and younger with Title V funding.

Several BFH programs aim to increase protective factors and decrease risk factors among Pennsylvania youth. Three partner organizations in Philadelphia implement evidence-based mentoring programs that are associated with positive social, behavioral, and academic outcomes. Additionally, the Olweus Bullying Prevention Program is provided in community-based settings and aims to enhance positive behaviors and interpersonal relationships with participants' peers.

The BFH prioritizes providing services to LGBTQ youth in Pennsylvania, who experience a higher rate of health disparities than their heterosexual peers. Programming for LGBTQ youth includes suicide prevention training and coalition building activities with ally organizations to help them become Safe Space-certified. BFH partners also provide a drop-in health center for youth to obtain health care and social services. Training is provided to medical, behavioral health, and social service providers on a variety of topics including health disparities, appropriate standards of care for LGBTQ individuals, and LGBTQ cultural competency.

The BFH currently supports gap-filling, direct teen pregnancy prevention and reproductive health services through the state's Health Resource Centers and Family Planning Councils and also provides direct behavioral health services to LGBTQ youth. Enabling programming developed to improve protective factors among youth and prevent bullying is also supported by Title V. The BFH sees an opportunity to enhance existing strategies and develop a system-level strategy addressing mental and behavioral health.

Capacity to Serve Children with Special Health Care Needs

Due to the broad range of care and coordination needed to meet the needs of the CSHCN population, the BFH supports a variety of direct, support, and referral services across the state to support CSHCN in their communities. In the creation and implementation of programs, the BFH ensures that the National Consensus Standards for Systems of Care for Children and Youth with Special Health Care Needs (CSHCN) are incorporated. The BFH addresses domains directly within the purview of Title V funding, such as Identification, Screening, and Referral; Access to Care; Medical Home; Community-Based Services and Supports; and

Transition to Adulthood. Other domains are addressed through partnerships including state and federal agencies, stakeholder agencies, and other partners.

Services provided to this population are targeted towards individuals and families most in need; therefore, the BFH serves those blind and disabled individuals under age 16 who receive Supplemental Security benefits from Title XVI to the extent that those services are not provided by Title XIX (Medical Assistance). Staff from the BFH collaborate with staff from the Department of Human Services Office of Medical Assistance Programs (OMAP) to avoid duplication of services and ensure that appropriate referrals and information are shared.

Therefore, the BFH programs ensure that children and families of CSHCN are active, core partners in decision making in all levels of care. The services and supports provided to CSHCN and their families are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner.

The BFH offers support and advocacy programs such as Community to Home, Special Kids Network Helpline and Leadership and Development Training. These programs reach statewide with evidence-based care coordination, outreach, training, and connecting individuals to resources. CSHCN and their families are key participants within these programs and are involved in decision-making at all levels.

The BFH also provides comprehensive, multi-disciplinary health-related services to individuals with certain conditions. The comprehensive Specialty Care Program provides care coordination and information and education provided by hospitals and community organizations. Through the BFH brain injury programs, including Acquired Brain Injury Program, Traumatic Brain Injury (TBI) and Opioid, and BrainSTEPS, the BFH offers brain injury education, brain injury rehabilitation services, and assistance with integrating back to a school environment following a brain injury. The BFH partners with the Tuscarora Intermediate Unit to provide referral and follow-up services to infants who fail a hearing screening. BFH staff works with these partners to educate clinicians and parents on the importance of screening and early intervention for better hearing outcomes. Additionally, the BFH’s memorandum of understanding with the Department of Aging (Aging) allows the BFH to use Aging’s Pharmaceutical Assistance Contracts for the Elderly Program’s claims processing and administrative functions to provide metabolic formula for CSHCNs for conditions including spina bifida, cystic fibrosis, MSUD, and PKU. The MOU allows the BFH to expand the number of accessible pharmacies and consolidate claims processing through a single administrative agency.

The county and municipal health departments provide CSHCN with services that include home visiting for at risk families, referrals to early intervention, a Medical Home Community Team for CSHCN in Philadelphia, and the Philadelphia Special Needs Consortium, which includes family members, providers, and other professionals to strengthen the system of care.

The BFH continues to administer programming aimed at providing children with a medical home and well-coordinated, family-centered care. Other components of a well-functioning system, including transition, may require the development of new system-level strategies. Additionally, CSHCN are more likely to have experienced ACEs as compared to children without special health care needs. A new strategy aimed at supporting children, including

CSHCN, with adverse experiences or experiences with trauma may need to be developed to address this.

Title V Program Partnerships, Collaboration and Coordination

The BFH is one of the many agencies and organizations that serve the MCH populations in Pa. It is through partnerships, collaboration, and coordination with other entities that the BFH and the state's Title V program can meet the needs of the women, mothers, infants, children, CSHCN, and adolescents in Pa.

A table listing all of the BFH's partnerships can be found in Supplement I.

As part of the needs and capacity assessment, BFH's Title V program staff also coordinated efforts with staff from the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program, which is housed in the Department of Human Services' Bureau of Early Intervention Services and Family Supports. The BFH provided MIECHV staff with an overview of the Title V needs and capacity assessment process and timeline, shared survey tools, and proposed the joint dissemination of needs assessment findings to MCH stakeholders once the MIECHV assessment is complete. Coordination with MIECHV staff is ongoing and the BFH aims to continue to foster this relationship, even in non-needs assessment years, given that the MIECHV and Title V programs engage and serve some of the same MCH population in Pa.

Agency Capacity: Agency Meeting

Overview

In order to better evaluate statewide capacity of other DOH bureaus and state agencies that also serve the MCH populations in Pennsylvania, the BFH held an agency meeting as part of its Needs and Capacity Assessment. The objectives of the agency meeting were to provide an overview of the services that Title V provides, to identify opportunities for collaboration with other state partners, and to seek input from BFH staff and agency partners on the priorities that will direct BFH work funded by the Title V MCHSBG over the next five years. A goal of this process was to evaluate existing interagency capacity to serve MCH populations and to prevent a duplication of efforts.

The meeting was held on Monday, November 18, 2019. Secretary Levine opened the plenary session, at which BFH staff described the purpose of Title V and presented the top Title V health priorities identified through the needs assessment. Afterward, over 50 staff members from the BFH, other bureaus and offices within the DOH (Bureau of Health Promotion and Risk Reduction, Bureau of Community Health Services, Office of Policy, Office of Operational Excellence/Office of Health Equity) and DHS broke out into working groups for focused discussion. Working group discussions took place throughout the day and were divided out by Title V population domain. Each discussion was facilitated by a BFH staff member and was guided by a standardized facilitation guide. The agenda for the day as well as the facilitation guide used to direct conversation are included in the Appendix (Supplements J and K).

During the discussion sessions, participants had an opportunity to review and comment on the data briefs, were asked to offer input on the Title V priorities that stakeholders had ranked highest at the regional prioritization events and through the prioritization web survey, and had an opportunity to rank the remaining priorities under consideration. Participants were reminded to frame their comments and feedback within the frameworks of organizational capacity and health equity. BFH staff took notes during the focused discussions, and the input provided is summarized below.

Feedback on Data Briefs

Prior to the start of each discussion session, an overview of the data brief for that population domain was provided. Participants had an opportunity to ask questions and comment on the data briefs. Common comments, recommendations, and questions are described below.

Several staff from the Bureau of Health Promotion and Risk Reduction (BHPRR) indicated that the data briefs did not focus on vulnerable populations that can be characterized using Medicaid data. BFH staff explained that HRSA requires a state-level assessment of health status for the purpose of the Needs and Capacity Assessment but that specific populations would be targeted in the development and implementation of strategies.

Additionally, staff from the BHPRR's Oral Health Program suggested that the oral health data presented in the data briefs does not highlight the high prevalence of tooth decay present among children in low-income households. Program staff also indicated that data from school health screens suggest that tooth decay is common among children in Pa. and that the NSCH's sample size is too small and limited in scope to demonstrate that.

BFH staff commented that, while the quality of child injury data is improving, such data only includes emergency room visits. If possible, it would be helpful to have data about the injuries that do not necessitate a visit to the emergency room.

Finally, several participants mentioned that, while Pennsylvania may be outperforming the national average for certain maternal and child health indicators, that does not mean that there is not an opportunity to improve performance in the state.

Discussion Sessions: Existing Capacity, Gaps, Challenges, and Collaboration

The primary takeaways from the discussion sessions are summarized below by Title V population domain. In addition to discussing where there is existing capacity and infrastructure that may be levied when addressing the newly proposed Title V priorities, the BFH aimed to identify gaps in the provision of services, opportunities for collaboration, and anticipated challenges of implementation.

Women/Maternal Health Discussion Session

- Existing Capacity

- The obesity/nutrition and substance use/mental health task forces which were assembled as part of the State Health Improvement Plan (SHIP) may be useful resources.
- The priority associated with maternal morbidity and mortality will align with the work of the Maternal Mortality Review Committee (MMRC). The MMRC will have actionable recommendations which, once available, may be useful in informing Title V strategy development.

- There is existing collaboration between DHS and DOH/BFH on Moving on Maternal Depressions (MOMD) to address and coordinate efforts around maternal depression services and screening across different programs.
- DHS has a Maternity Care Coalition Mom Mobile which contracts with Managed Care Organizations (MCOs). The mobile provides mothers with transportation to medical care visits and conducts home visits.
- Strategies implemented through BFH's existing Centering Pregnancy and Home Visiting programs would still be relevant to the new women/maternal health priorities on maternal morbidity.
- BHPRR's Health Literacy Program has mini grants with hospitals in which information that is sent out to new mothers is reviewed and revised to reflect the appropriate literacy level.

- Gaps in the Provision of Services

- BFH staff indicated that there is a lack of capacity for connecting women with depression to services. While screening for depression is improving and becoming a more commonly offered service, making the connection to treatment is a challenge.
- BHPRR staff reported that there is always a need for more infrastructure to address and prevent diabetes among women and mothers in Pa.
- BHPRR staff indicated that there is a need for more efforts around health literacy.

- Opportunities for Collaboration

- BHPRR would like to add messaging about oral health, smoking, and chronic disease to existing BFH programming and strategies.
- The Pennsylvania Perinatal Quality Collaborative has been focusing on maternal morbidity and mortality with 80% of hospitals participating – collaboration may be feasible.
- BHPRR is interested in collaborating on strategies related to primary prevention of chronic disease among women prior to pregnancy and on tobacco use during pregnancy.
- Some states have lengthened the period for Medicaid reimbursement to one year after pregnancy instead of 60 days – is collaboration with DHS on policy change possible?
- Moving Beyond Depression is being implemented by Lancaster Nurse Family Partnership, and HealthyStart is also addressing depression through home visiting.

- Potential Barriers and Challenges in Implementation

- While there is a lot of emphasis on mortality, there is less focus on and understanding of morbidity.
- Racism is a huge component of maternal mortality. Interventions addressing maternal mortality and morbidity should be equitable and address racism.
- Lack of male involvement could be a barrier to certain strategies.
- Substance use and the associated stigma could prevent some women/mothers from seeking services.

Infant/Perinatal Health Discussion Session

- Existing Capacity

- BHPRR's state physical activity and nutrition grant addresses breastfeeding initiation and continuation.
- A US Centers for Disease Control and Prevention (CDC) grant on racial and ethnic approaches to community health held by Penn State Health and Allegheny County, is addressing gaps/disparities in breastfeeding and breastfeeding continuation.
- BHPRR's oral health program is working with the PA Head Start Association and other childhood care centers to raise awareness of preventive care.
- Pennsylvania Special Supplemental Nutrition Program for Women, Infants and Children (WIC) and the Child and Adult Care Food Program (CACFP) through the US Department of Agriculture (USDA) provide training on infant feeding practices to licensed childhood facilities.
- DHS' Office of Childhood Development and Early Learning (OCDEL) has a program that consists of text messages to caregivers on safe care of children at different ages and includes messaging around safe sleep.
- National Text for Baby text messaging program sends messages around infant health during pregnancy and postpartum.
- NurturePA (Allegheny County) has a messaging program staffed by mentoring parents (parents with older children).
- BFH has existing Title V home visiting programming offered through the county/municipal health departments (CMHDs) and has funded work on health literacy among nurses.
- MIECHV has an existing home visiting program.

- Gaps in the Provision of Services

- DHS/OCDEL indicated that more support is needed for mothers who wish to continue breastfeeding through six months.
- There is a lack of birthing centers across Pennsylvania, particularly in rural counties. Women may be delivering in emergency departments where there is a lack of preparedness. Similarly, high-level care obstetric services and neonatal intensive care units (NICU) are not evenly distributed across the state.
- The delivery of culturally competent/relevant care is important – some of the sleep-focused work does not consider harm reduction strategies for women in certain cultures that will be co-sleeping.

- Opportunities for Collaboration

- BHPRR's state physical activity and nutrition grant is required to fund and report on breastfeeding initiatives.
- BHPRR may have opportunities for collaboration around pre-term birth and oral health.
- OCDEL's Early Learning GPS program, which consists of text messages to caregivers on safe care of children at different ages, could include messaging related to breastfeeding or other infant health issues.
- There is an opportunity to collaborate with MIECHV or programs like Promotores.

- Potential Barriers and Challenges in Implementation
  - Infrastructure is a challenge, especially in rural areas.
  - Better support is needed for home births – reaching midwives with messaging or health programming is a challenge.

Child Health Discussion Session

- Existing Capacity
  - BFH has some programming addressing bullying and mental health for youth, positive youth development, positive male involvement, traumatic brain injury, and mentoring that could be expanded to include younger children.
  - BHPRR’s state physical and nutrition grant does work related to adverse childhood experiences (ACEs), including weight bias/stigma.
  - BFH’s existing Traumatic Brain Injury (TBI) program and interactions with providers around mental and behavioral health could be considered existing capacity.
  - The Office of Health Equity’s (OHE) Pa. Interagency Health Equity Team (PIHET) has working groups on physical activity, nutrition, and mental health.

- Gaps in the Provision of Services
  - There is a lack of programming related to child bullying and mental health in rural areas.
  - Insurance coverage for mental health coverage among children is often considered insufficient.
  - There is a lack of programming related to vaping and substance use among youth.

- Opportunities for Collaboration
  - OHE’s PIHET is working to address physical activity, nutrition, and mental health, and there are opportunities for collaboration.
  - BHPRR’s Oral Health program would like to collaborate with Title V to pay for sealants for children between the ages of 6 and 9.
  - There are other opportunities to partner with BHPRR on work related to their state and Physical Nutrition Grant.
  - OHE collaborates with DHS and Department of Community and Economic Development (DCED) on mental health and other social determinants of health.
  - OCDEL partners with the Pennsylvania Key program (provides early childhood program information) to consult on child mental health, and there may be an opportunity for collaboration.
  - Collaboration is possible with the Office of Mental Health and Substance Abuse Services (OMHSAS) and the Department of Drug and Alcohol Programs (DDAP) regarding trauma-informed care and services.
  - ACEs has training called Handle with Care: police have a relationship with schools; if a child has any connection with police or violence, police contact the school and ask that the child be handled with care; teachers are notified so they can support the child.
  - Department of Education (PDE) could be a partner in developing training related to ACEs.

- Potential Barriers and Challenges in Implementation

- There is a lack of broadband support and infrastructure for telehealth/telemedicine applications.
- Schools are under-resourced and may not be the ideal setting to reach children.
- Stigma surrounding mental health may present a challenge.

Adolescent Health Discussion Session

- Existing Capacity

- BFH has some existing programming in its Division of Community Systems Development and Outreach (CSDO) and its Division of Child and Adult Health Services (CAHS) that addresses protective factors and developmental assets for adolescents, including Coaching Boys into Men.
- BHPRR has some programming around tobacco cessation, vaping, and addiction for adolescents and youth. This programming provides information to schools.

- Gaps in the Provision of Services

- There is insufficient infrastructure and number of providers who can address child mental and behavioral health.
- Mental health needs among LGBTQ youth are not sufficiently met.
- There is a need for trauma-informed care and programming.
- Health messaging for adolescents needs to be improved.
- There is a lack of physical activity-related resources in schools.

- Opportunities for Collaboration

- Existing capacity exists for addressing obesity and physical activity programming in BHPRR, but the primary focus has been younger children – there is a possibility for collaboration to expand that work to youth/adolescents.
- DDAP would be a good partner for addressing mental health and dual diagnosis treatment for adolescents.
- PIHET's working groups on obesity, physical education and water consumption could be engaged if one strategy was related to policy change.

- Potential Barriers and Challenges in Implementation

- Guardians and caregivers can be a barrier to adolescents receiving certain programming.
- Programming for adolescents is often delivered through schools, but there are barriers and levels of approval that may limit which programming is accepted and offered through schools.
- There is a shortage and aging of mental/behavioral health providers.
- Stigma is often a barrier when addressing mental health.
- Adolescents have access to a lot of information about health, not all of which is credible depending on the source; developing the appropriate means of messaging and reaching youth may be a challenge.
- It may be challenging to identify and treat root causes of a problem among youth rather than just the symptoms.

Health of CSHCN Discussion Session

- Existing Capacity

- There is existing programming in CSDO (i.e., Community to Home, Male Involvement, Community Health Worker model) and CAHS for CSHCN, including work supported through the CMHDs.
- BFH has a good relationship with Pennsylvania's hospitals and is working to develop a relationship with federally qualified health centers (FQHCs).
- BHPRR's Oral Health Program is working with the University of Pennsylvania so that providers can get continuing education credits to learn about serving CSHCN patients at dental offices.

- Gaps in the Provision of Services

- Service provision in rural areas is a challenge for CSHCN.
- There is a lack of programming related to sex, sexuality, and building skills needed to navigate contraception among CSHCN. Providers have asked for training around teaching CSHCN about consent and protection.
- Data suggest that bullying is more common among CSHCN – there is a lack of programming related to bullying and substance use within this population.
- There is a lack of support for CSHCN who are aging beyond the expected lifespan of their condition, even just into adolescence.
- There is a lack of dental health professionals, many of whom will not provide services for CSHCN due to lack of training or equipment. Some providers do not accept CHIP.
- Improvement is needed to provide culturally competent care and navigation services, especially to patients who speak a language other than English.

- Opportunities for Collaboration

- A big area for collaboration would be with families and caregivers of CSHCN – increased family and caregiver involvement is needed.
- It is important to consider existing partnerships (i.e., with DHS) and expand them to address more complex issues – ACEs and trauma can move a child from being healthy to a child with special health care needs.
- There is a need to identify partners that can facilitate the provision of advanced and specialty care to a population that often receives preventive care.
- Collaboration with the Department of Education (PDE), schools and other members of a child's network of support/care is needed.
- Collaboration with the correction system is needed to ensure the CSHCN are diverted to services rather than to a juvenile justice system by default.
- There is a need to develop more relationships with non-profit organizations.

- Potential Barriers and Challenges in Implementation

- Telehealth may be a promising strategy, but it isn't appropriate for all patients and there are challenges associated with broadband, especially in rural areas where the service may be most needed.
- Providers often focus on survivability rather than ensuring that their patients are living a fully realized life within reason to their condition.

- Medical advancements are increasing lifespan beyond scientific knowledge of how to provide care.

Workforce Capacity and MCH Competencies of Title V Staff

Overview

The final step of the capacity assessment was to evaluate the strengths and needs of the existing Title V program's workforce. This portion of the assessment was accomplished through compilation of existing workforce data and internal survey of Title V program staff.

Title V Funded Staff Positions

The state's Title V program currently funds 59 full-time staff located in Harrisburg, Pa. and 53 local Title V staff who operate statewide through the county and municipal health departments (Table 1). While most staff operate out of the BFH where the block grant is housed, other positions across the DOH that support the BFH or serve MCH populations are also supported by Title V.

Table 1: Title V-Funded Staff Positions as of March 2020

Bureau/Office	Number of Title V Funded Positions	Location
Bureau of Family Health, Bureau Office	2	Harrisburg, Pa.
Bureau of Family Health, DBO	11	Harrisburg, Pa.
Bureau of Family Health, CAHS	13	Harrisburg, Pa.
Bureau of Family Health, CSDO	13	Harrisburg, Pa.
Bureau of Family Health, NSG	16	Harrisburg, Pa.
Bureau of Community Health Systems	1	Harrisburg, Pa.
Bureau of Epidemiology	1	Harrisburg, Pa.
Office of Legal Counsel	1	Harrisburg, Pa.
Office of Health Equity	1	Harrisburg, Pa.
Local Title V Staff	53	Statewide
Total	112	

SOURCE: Pennsylvania Title V staffing reports, 2020. Department of Health, Bureau of Family Health.

Leadership

The BFH's director, division directors, Title V Block Grant coordinator and Maternal and Child Health epidemiologist serve as the lead MCH-related positions that contribute to planning, evaluation, and data analysis capabilities. Below are the names and qualifications of the current staff:

- Director of the Bureau of Family Health: Tara Trego

  Tara Trego was appointed as the director of the BFH in December 2018 and serves as the state's Title V MCH Director. Tara has worked for the BFH for over 12 years and has 16 years of public health experience. She holds a master's degree in Health Education.

- Director of the Division of Child and Adult Health Services: Vacant

  Following the recent departure of former division director, Kelly Holland, this director position is currently vacant. Given the state employee hiring freeze in place due to the novel coronavirus (COVID-19) pandemic, this position can only be filled if an exemption is approved. In the interim, Bureau Director Tara Trego will oversee this division.

- Director of the Division of Bureau Operations: Erin McCarty

  Erin McCarty has been the director of this division since April of 2017. Erin holds a Master of Public Health degree and has over 13 years of public health experience. Erin is also the Title V CSHCN director.

- Director of the Division of Newborn Screening and Genetics: Stacey Gustin

  Stacey Gustin was named as the director of this division in February 2020. Stacey has worked in the BFH for eight years and has 13 years of public health experience. She holds a B.S.N. degree in Nursing.

- Director of the Division of Community Systems Development and Outreach: Cindy Dundas

  Cindy Dundas has been the director of this division since November 2016. Cindy has worked in the BFH for 18 years and has over 20 years of public health experience, in addition to 10 years of experience in the mental health/intellectual disability field. She holds a bachelor's degree in psychology and is the parent of a CSHCN.

- Maternal and Child Health Epidemiologist: Nhiem Luong, DrPH

  Nhiem Luong was hired as the MCH epidemiologist for the BFH in October 2018. As MCH epidemiologist, Nhiem conducts analysis on various MCH datasets and provides BFH staff with technical assistance and support related to accessing, analyzing and interpreting data, and summarizing results. Nhiem holds a DrPH degree and has over 20 years of experience in medicine, public health and research.

- Title V Block Grant Coordinator: Caryn Decker

  Caryn Decker was named the Title V block grant coordinator in May of 2020. Caryn holds a Master of Public Health degree and has over five years of public health experience. Caryn has worked in the BFH for nearly two years and also coordinated the 2020 Title V Five-Year Needs and Capacity Assessment.

Tenure and Public Health Experience

In order to gauge the tenure of current Title V staff, BFH staff were surveyed on the amount of time that they have been in their current position as well as their public health experience. More than half of the BFH's current Title V workforce (53%) have been in their positions for less than three years. When broken out by job title, it is evident that most newer hires are program-level staff (public health program administrators and public health program assistant administrators). This suggests that there has been some consistent turnover over the past three years. In contrast, most managers and directors (89%) have been in their position for at least three years or more, suggesting that there is considerable institutional knowledge of Title V at the management level. The combination of experienced management staff and new program staff who may bring a fresh perspective to their work is a strength of the BFH's Title V workforce. However, the concentration of Title V knowledge and experience at the management level may suggest that continued training on the mechanics of the MCHSBG and its framework at the program-staff level may be warranted.

When all staff were asked about work experience in public health (including but not limited to program development/implementation or health promotion), approximately 70% of staff reported having worked in the field of public health for more than five years with 43% indicating that they had been in the field for 10 years or more. This suggests that most staff in the bureau have had some public health work experience, including new hires. Additional information regarding staff knowledge of competencies specific to MCH is described below.

MCH Competencies

As a first step, Needs Assessment Steering Committee members were surveyed on which MCH competencies should be assessed among Title V staff. The three competencies that Needs Assessment Steering Committee members identified as being the most important to assess among staff were MCH knowledge base/context, critical thinking, and working with communities/systems. The following definitions were utilized: 1) MCH knowledge base/context – knowledge and skills related to the MCH specialty area within the larger field of public health; 2) Critical thinking – the ability to identify an issue or problem, frame it as a specific question, consider it from multiple perspectives, evaluate relevant information, and develop a reasoned resolution; and 3) Working with communities and systems – knowledge of how different components such as norms, laws, resources, infrastructure, and individual behaviors interact at multiple levels, including individual organizations, the collective stakeholders, and the communities where the children, youth, and families reside.

Program staff were then asked to complete a self-assessment indicating the extent to which they felt they could perform each competency. Data from the self-assessments were analyzed to identify strengths, weaknesses, and staff-identified areas where additional training is desired.

- MCH knowledge base and related context

Data related to the MCH knowledge base and related context already existed from a workforce development survey that had been disseminated in February 2019. Staff were asked how strongly they agreed with the statement that they could perform each competency. Staff selected one of five responses – strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree. Each response was weighted – strongly agree (five points), agree (four points), etc. Weighted average scores were calculated, and competencies with the three highest and three lowest weighted average scores were identified. There were 44 respondents to this survey.

The three competencies related to the MCH knowledge base and related context that staff felt **most** strongly that they could perform were as follows:

- I can describe barriers restricting access to care.
- I can describe a broad range of factors affecting the health of a community (such as income, safe neighborhoods, etc.).
- I can describe health disparities within MCH populations; health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health.

The three competencies related to the MCH knowledge base and related context that staff felt **least** strongly that they could perform were as follows:

- I can apply the Health Belief Model in the design of interventions targeting MCH populations; the Health Belief Model is a theory of how people make changes in their behavior.
- I can describe the limitations/gaps of Title V programs provided to MCH populations.
- I can apply the socioecological model in the design of interventions targeting MCH populations; the socioecological model is a framework for explaining how layers of influence intersect to shape a person's behavior.

Staff were then asked how much of a priority training for each competency was to them. They could select one of three responses – high, medium, or low priorities. The competencies with the highest weighted averages, indicating highest priority for training, were as follows:

- I can describe strategies to address health disparities within MCH populations.
- I can describe challenges to advancing health equity (which means everyone has the opportunity to attain their highest level of health).
- I can identify resources that can be used to improve the health of a community.

Overall, the results of this survey indicated that most staff did not feel that they could describe the limitations/gaps of Title V programming or apply behavioral models in the design of interventions for MCH populations. Staff felt most strongly that they understand social determinants of health and can describe health disparities and barriers to care. While the survey results suggest that additional capacity could be built around understanding Title V and intervention models, those competencies were not identified by staff as high training priorities. In fact, even though the survey results suggest that staff felt most confident in their understanding of health disparities and social determinants of health as they relate to MCH, these areas were also identified by staff as their highest priority areas for ongoing training.

- Critical Thinking and Working with Communities and Systems

To complement the existing data on MCH knowledge base, Title V program staff were asked to take a brief self-assessment that focused on the other two competencies chosen by the steering committee – critical thinking and working with communities/systems. Staff were asked how strongly they agreed with the statement that they could perform each competency. Staff selected one of five responses – strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree. Each response was weighted – strongly agree (five points), agree (four points), etc. Weighted average scores were calculated and competencies with the three highest and three lowest weighted average scores were identified. There were 44 respondents to this survey.

The three competencies related to critical thinking and working with communities and systems that staff felt **most** strongly that they could perform were as follows:

- I can identify evidence-based practices to address health needs within MCH populations.
- I can evaluate various perspectives, sources of information and approaches when designing interventions or program targeting MCH populations.
- I can present and discuss a rationale for a proposed program that is grounded in research and evidence.

The three competencies related to the critical thinking and working with communities and systems that staff felt **least** strongly that they could perform were as follows:

- I can identify new opportunities for stakeholder engagement in Title V programming.
- I can identify the extent to which stakeholders are engaged in Title V programming.
- I can identify and describe community and family collaboration models applicable to my work.

Staff were then asked how much of a priority training for each competency was to them. They could select one of three responses – high, medium, or low priorities. The competencies with the highest weighted averages, indicating highest priority for training, were as follows:

- I can identify and describe community and family collaboration models that are applicable to my work.
- I can translate research into policies and programs.
- I can use population data to determine the needs of an MCH population.

Overall, respondents felt they had the most knowledge around identifying evidence-based practices and program/intervention design. Respondents felt less knowledgeable about stakeholder engagement and family collaboration, suggesting that training related to working with communities and systems may be merited in order to build capacity in that area. This is consistent with staff interests, as, when asked about training priorities, respondents rated the highest training priority as the competency in identifying and describing community and family collaboration models applicable to their work. The next highest training priorities identified by respondents were translating research into policies and programs and using population data to determine population needs.

Prioritization

Collaboration with Expert Consultants: Center of Excellence in MCH

At the start of the prioritization process, the BFH identified a team from the Center of Excellence in MCH Education, Science, and Practice Program at the Johns Hopkins Bloomberg School of Public Health (JHBSPH) as part of a technical assistance request to HRSA's MCHB. The members of the JHBSPH team that collaborated with BFH staff included Donna Strobino, PhD, Pamela Donahue, MD, and Carrie Wolfson, a doctoral candidate. As part of their work, the JHBSPH team developed a summative report that described their contributions to the prioritization process, including the literature review that informed the value-selection and ranking process, their assistance with facilitation of the regional prioritization meetings, and the methods and results of the quantitative and qualitative analyses. Components of their report, including sections of narrative and tables that they developed, are included and cited below.

Process Development

Figure 5: Prioritization Process

i. Identification of values to guide selection of priorities

ii. BFH identification and scoring of 21 priorities; subsequent selection of four potential priorities for each population domain

iii. In-service training of BFH staff to build capacity to facilitate and take notes during regional meetings

iv. Regional meetings with stakeholders to collect feedback and ranking of potential priorities

v. Additional efforts to collect feedback and ranking of potential priorities – events and web survey

vi. Analysis of stakeholder feedback; solicitation of additional feedback from agency partners and BFH staff

vii. Final selection of priorities

SOURCE: Adapted from PA Title V Five-Year Needs and Capacity Assessment: Stakeholder Engagement in Prioritization, Wolfson et al. 2019.

In consultation with the team from the JHBSPH, the steering committee developed an iterative process to select priorities that was designed to incorporate feedback from stakeholders using a systematic process informed by evidence from the literature and the experiences of other states (Wolfson et al. 2019). This process included initial identification and scoring of potential priorities by the steering committee, which were then ranked by stakeholders during working group meetings. These rankings were then used by the steering committee to inform final priority selection. An overview of the steps of the process are found in Figure 5 and are described in greater detail below.

Literature Review and Identification of Values

A literature review was conducted by the JHBSPH team to identify a broad range of public health values and strategies that have been used to guide prioritization processes. Consulted resources included academic references, public health textbooks and resource guides, government agencies, and reports from other states about their prioritization processes in past and ongoing Title V needs assessments (Wolfson et al. 2019). Through this review, 36 potential public health values were identified within seven broad domains, and a general structure was identified for the prioritization process.

The Needs Assessment Steering Committee and the JHBSPH team determined that identifying guiding values would be an important step in the prioritization process. The literature suggested that prioritization processes are improved by an explicit definition of values (judgments about what constitutes a need) because, even when undefined, values still impact decision-making. Implicit values may be inconsistently applied by different decision-makers and can create the appearance of an arbitrary process. As such, developing consensus on the values that are most important when selecting among competing priorities was integrated into the prioritization process (Wolfson et al. 2019).

The steering committee was presented with the list of 36 potential public health values within seven themes identified from relevant literature, and they selected 15 values across the themes to guide priority setting in Pennsylvania (Table 2). The initial list of values identified was reviewed by the DOH's Office of Policy and the DOH's leadership, namely Secretary Levine, to ensure that the values were consistent with the agency's mission before the BFH adopted them as part of their framework. The steering committee then further reduced the list to six values that stakeholders, given their unique perspectives, were asked to consider in ranking of potential priorities (see Table 2).

Table 2: Values Informing the Prioritization of MCH Needs in PA's 2020 Title V Five-Year Needs and Capacity Assessment

Theme	Value	Considered by Stakeholders
Impact	Magnitude and trends of the problem	✓
	Seriousness or severity of the problem	✓
Changeability	Ability for impact	
	Magnitude and longevity of potential benefit	
Acceptability	Community and stakeholders view issue as a problem	✓
	Interventions to address issue are acceptable to the community	✓
	Problem aligns with federal and/or state goals and mission	
Feasibility	Evidence-based or informed strategies are available	
	Organizational capacity to address issue and implement solutions	
Equity	Problem disparately impacts individuals based on race, ethnicity, sexual orientation, gender identity, geographic location, age, poverty status, disability/special health care need, or other aspects of social disadvantage	
Measurability	Problem can be measured/tracked.	
Externalities	Potential for collaboration/partnerships	
	Response to the problem fosters involvement of consumers/clients and their families.	✓
	Addressing the problem could improve other priority areas	
	Possibility for unintended negative consequences	✓

SOURCE: Adapted from PA Title V Five-Year Needs and Capacity Assessment: Stakeholder Engagement in Prioritization, Wolfson et al. 2019.

Initial Development and Scoring of Potential Priorities

In order to develop the initial list of priorities, the BFH considered all of the National Outcome Measures (NOMs) and National Performance Measures (NPMs) put forward for Title V by HRSA, as well as the corresponding data that had been analyzed as part of the characterization of MCH population health status. NOMs and NPMs were then scored based on the list of pre-identified values and the BFH's data briefs, which summarized the state and national health data that had been analyzed and data from the focus groups and web survey related to social determinants of health in Pa. The preliminary list of 21 priorities was also reviewed by the DOH Office of Policy and Secretary Levine. It was determined that all of the potential priorities could be feasibly addressed by the agency and that many of them were in direct alignment with the secretary's initiatives related to maternal and child health in Pennsylvania. The priorities selected are listed below in Table 3.

Table 3: Potential Priorities for Stakeholder Feedback and Ranking

Domain	Potential Priority
Women/maternal health	Reduce or improve maternal morbidity and mortality, especially among disparate populations
	Reduce substance use among women and pregnant women
	Reduce rates of perinatal depression and related symptoms
	Increase the percent of women receiving a preventive medical visit/medical care
Perinatal/infant health	Reduce the rate of pre-term births, especially among disparate populations
	Reduce rates of infant mortality (all causes), especially among disparate populations
	Improve rates of breastfeeding, especially among disparate populations
	Improve the percent of eligible newborns screened for heritable disorders with on time physician notification for out-of-range screens that are followed up with in a timely manner
Child health	Increase the percent of children receiving a preventive medical visit/medical care
	Reduce rates of child mortality and injury, especially among disparate populations
	Decrease bullying
	Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs
Adolescent health	Reduce or improve adolescent morbidity and mortality, especially among disparate populations
	Decrease bullying
	Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs
	Decrease the adolescent/teen pregnancy rate, especially among disparate populations
Health of children and youth with special health care needs (CSHCN)	Reduce the rate of bullying among children and youth with special health care needs
	Improve access to and use of transition services among children and youth with special health care needs

Domain	Potential Priority
	Improve the percent of children and youth with special health care needs who receive care in a well-functioning system
	Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs
Cross-cutting and systems building	Strengthen Title V staff's capacity for data-driven and evidence-based decision making and program development

Staff Training: Prioritization Strategy and Facilitation Best Practices

The JHBSPH team conducted an in-service training with BFH staff as part of a technical assistance request to HRSA's MCHB.

The goal of the training was to build Title V staff capacity to utilize data to identify and prioritize needs in partnership with stakeholders. The training was designed to not only prepare BFH staff for this five-year needs and capacity assessment, but also to serve as a foundation for future assessments. As part of the in-service training, the JHBSPH team described the literature review that informed the development of the prioritization process and the methods that would be employed to seek stakeholder feedback and rankings at a series of regional prioritization meetings. Additionally, the JHBSPH team engaged BFH staff in conversation about how to best elicit feedback from stakeholders and provided an overview of best practices for effective working group facilitation and notetaking.

The in-service training allowed for idea sharing between BFH staff, who had unique experiences engaging with the MCH stakeholder community in Pa., and the JHBSPH team. Following the training, the JHBSPH team and the steering committee collaboratively developed the final ranking tools that would be utilized at the regional prioritization meetings.

Regional Prioritization Meetings

In September and October 2019, six regional meetings were planned to collect stakeholder feedback on the potential Title V priorities. One meeting was planned in each of the DOH's community health districts in order to ensure that meetings were held across the state, and the locations of the meetings were selected so that they would be accessible to stakeholders. Locations were accessible by public transportation or had sufficient parking, were open in the evening, and allowed food and drink. Prior to scheduling each meeting, the BFH conducted a survey of Pennsylvania's MCH stakeholders, including service providers and patients/service recipients and their family members in order to ascertain what time of day and which day(s) of the week would be most convenient for the regional meetings. Based on the feedback from that survey, the BFH scheduled meetings in the evening in the following cities: Pittsburgh, Erie, Scranton, Williamsport, Norristown, and Harrisburg.

Invitations to the regional prioritization meetings were distributed via an email distribution list that included all current MCH vendors and partners, as well as other organizations, persons, and groups with an interest or stake in MCH in Pennsylvania. Information regarding the events was also posted to the DOH's social media pages (Twitter and Facebook), and service providers were asked to post fliers in their offices and to share the emails and invitations with their service recipients, community, and networks. Across the regional meetings, there were a total of 84 attendees; 20 attended the meeting held in Pittsburgh, 10 attended the meeting in Erie, six attended the meeting in Scranton, 26 attended the meeting in Norristown, and 20 attended the meeting in Harrisburg. The meeting in Williamsport was cancelled due to a low response to the invitation. Most participants at the meetings were providers or professional stakeholders. Despite efforts to engage service recipients, family members, and caregivers, few family stakeholders attended the meetings, with only one family attendee in Pittsburgh, one in Erie, and none at the other meetings.

The agenda for the regional meetings (Appendix, Supplement J) included a plenary session with a presentation of the Title V Needs and Capacity Assessment process, the results of qualitative and quantitative data collection by BFH (data briefs were provided to each attendee), the objectives for the working groups, and the values guiding the process (Table 2). Following the plenary session, attendees met in smaller working groups to review and rank potential priorities. At each meeting there was one group focused on women/maternal health and perinatal/infant health, one on child health and adolescent health, and one on CSHCN. A separate working group for family members was conducted in Pittsburgh.

Working groups were facilitated by BFH staff or the JHBSPH team, with additional staff or JHBSPH team members serving as notetakers. Facilitators each followed the same facilitation guide in order to achieve consistency across groups and prioritization events (Appendix, Supplement K). Stakeholders had the opportunity to discuss the data presented in the data briefs and the guiding values. Facilitators then led a discussion about potential priorities for the relevant domains using the values to frame the discussion. Stakeholders were also asked if there were priorities not included in the list of potential priorities that should be considered. Feedback on the priorities was captured by the notetakers. Following the discussions, stakeholders ranked the potential priorities in order of importance on ranking sheets (one being the most important, four being the least important) [Sample from women/maternal health domain shown in Appendix, Supplement L]. Stakeholders were given the opportunity to rank priorities within any domain regardless of the group in which they participated. Data from the rankings were summed for the meeting wrap-up following the working groups activities. All meeting participants still in attendance were convened to report final thoughts and for the presentation of the meeting specific ranking results (Wolfson et al. 2019).

Web Survey: Priority Ranking

In order to gather input from stakeholders who were unable to attend the in-person prioritization events, the BFH made additional attempts to gather feedback from stakeholders about prioritization of needs at other in-person events and via survey. Ranking sheets were distributed at a health equity event and at an adolescent health event that BFH staff attended. The BFH also conducted an online survey that was distributed to the MCH stakeholder email distribution list as well as to all persons who attended the in-person prioritization meetings, as many in attendance expressed that their co-workers or agency partners would like an opportunity to rank the potential priorities. The survey instructions indicated that it was intended for stakeholders who did not attend one of the in-person meetings. If a survey respondent indicated that they had attended one of the in-person events, that respondent was not able to advance through to rank the priorities, as they had already done so at one of the regional events.

In total, there were 187 respondents to the online survey, of which 145 identified as providers and 42 identified as service recipients. Eighteen respondents indicated that they had attended a regional event or planned to attend an event. The survey allowed respondents to rank priorities for whichever domains they chose and to write in suggestions for additional priorities for BFH's consideration.

Analysis of Stakeholder Feedback

The JHBSPH team conducted quantitative and qualitative analysis of the stakeholder input on the proposed priorities. Rankings from each regional event were summarized and analyzed quantitatively. The average priority ranking was tabulated by domain, separately for each regional meeting, event, and the online survey. The global average ranking for priorities in each domain was based on an average of all stakeholder responses with equal weighting applied to each response regardless of meeting site or on-site/online completion of the ranking form. This approach was taken because of the marked variability in the number of attendees at each meeting and the number of respondents to the online survey (Wolfson et al. 2019).

Stakeholder feedback in the form of notes from the working groups at each prioritization event, written comments on the ranking sheets distributed during regional meetings and at other in-person events, and comments from the online survey were summarized and analyzed qualitatively. Qualitative analysis was guided by regular discussions of the data among the JHBSPH team and analytic memos that collated notes by population domain. Ranking data was compared between and within population domains and by regional meeting location, paying attention to concordance and discordance in participant responses. Qualitative findings were triangulated with the quantitative ranking results to ensure credibility of findings (Wolfson et al. 2019).

Findings

Summary of Quantitative Ranking Results by Title V Population Domain

For the women/maternal health domain, stakeholders ranked reducing or improving maternal morbidity and mortality, especially among disparate populations as the highest priority. The second-ranked priority for this domain was increasing the percent of women receiving a preventive medical visit/medical care (Table 4).

Table 4: Stakeholder Ranking of Proposed Title V Women and Maternal Health Priorities

Women/Maternal Health Priorities	**Global Rank (n=135)**
Reduce or improve maternal morbidity and mortality, especially among disparate populations	1
Increase the percent of women receiving a preventive medical visit/medical care	2
Reduce substance use among women and pregnant women	3
Reduce rates of perinatal depression and related symptoms	4

For the perinatal/infant health domain, stakeholders ranked reducing rates of infant mortality (all causes), especially among disparate populations, as the highest priority. The second-ranked priority for this domain was reducing the rate of pre-term births, especially among disparate populations (Table 5).

Table 5: Stakeholder Ranking of Proposed Title V Infant/Perinatal Health Priorities

Perinatal/Infant Health Priorities	Global Rank (n=117)
Reduce rates of infant mortality (all causes), especially among disparate populations	1
Reduce the rate of pre-term births, especially among disparate populations	2
Improve rates of breastfeeding, especially among disparate populations	3
Improve the percent of eligible newborns screened for heritable disorders with on time physician notification for out-of-range screens that are followed up with in a timely manner	4

For the child health domain, stakeholders ranked improving mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs as the highest priority. The second-ranked priority for this domain was a tie between increasing the percent of children receiving a preventive medical visit/medical care and reducing the rates of child mortality and injury, especially among disparate populations (Table 6).

Table 6: Stakeholder Ranking of Proposed Title V Child Health Priorities

Child Health Priorities	Global Rank (n=106)
Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs	1
Increase the percent of children receiving a preventive medical visit/medical care	2
Reduce rates of child mortality and injury, especially among disparate populations	2
Decrease bullying	3

For the adolescent health domain, stakeholders ranked improving mental health, behavioral health and developmental outcomes for children and youth with and without special health care needs as the highest priority. The second-ranked priority was reducing or improving adolescent morbidity and mortality, especially among disparate populations (Table 7).

Table 7: Stakeholder Ranking of Proposed Title V Adolescent Health Priorities

Adolescent Health Priorities	Global Rank (n=119)
Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs	1
Reduce or improve adolescent morbidity and mortality, especially among disparate populations	2

Decrease the adolescent/teen pregnancy rate, especially among disparate populations	3
Decrease bullying	4

For the health of children and youth with special health care needs domain, stakeholders ranked improving the percent of children and youth with special health care needs who receive care in a well-functioning system as the highest priority. The second-ranked priority was improving mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs (Table 8).

Table 8: Stakeholder Ranking of Proposed Title V Priorities for the Health of Children and Youth with Special Health Care Needs

Children and Youth with Special Health Care Needs Priorities	**Global Rank (n=95)**
Improve the percent of children and youth with special health care needs who receive care in a well-functioning system	1
Improve mental health, behavioral health and developmental outcomes for children and youth with and without special health care needs	2
Improve access to and use of transition services among children and youth with special health care needs	3
Reduce the rate of bullying among children and youth with special health care needs	4

Other Priorities Proposed by Stakeholders

As part of the needs and capacity assessment and the prioritization process, other needs that were not ultimately captured in the final set of priorities were identified. The priorities that were proposed by stakeholders are listed below by population domain (Table 9). The venue is listed as “working group” if the priority was discussed during the working group activity and “stakeholder” if the priority was listed only on a ranking sheet(s) [Wolfson et al. 2019].

Table 9: Other Priorities Proposed by Stakeholders by Title V Population Domain

Women/Maternal Health: Proposed Priorities	**Venue where recommended**
Improve access to services/systems coordination – better infrastructure, insurance coverage, cross agency coordination, availability of providers, transportation	Pittsburgh working group; Erie working group; Norristown working group
Provide adequate prenatal care	Scranton working group
Address institutional racism	Norristown working group
Improve oral health	Norristown working group
Decrease c-section rates among low risk groups	Norristown stakeholder
Increase parenting support to promote maternal child engagement	Harrisburg stakeholder
Address food insecurity and lack of nutrition education	Health equity summit stakeholder
Infant Health: Proposed Priorities	**Venue where recommended**

Improve navigation of services and availability of providers (particularly in rural areas)	Pittsburgh, Erie, and Scranton working groups; Harrisburg stakeholder
Improve childcare options for families	Erie working group
Follow up with preterm infants after discharge	Scranton working group
Reduce maternal obesity	Scranton working group
Reduce neonatal abstinence syndrome	Norristown working group
Improve access to mental health care for infants/infants whose parents have mental health issues	Norristown working group
Improve access to oral health care for infants	Harrisburg working group
Reduce lead poisoning	Norristown stakeholder
Mother and infant attachment	Harrisburg stakeholder
Child Health: Proposed Priorities	**Venue where recommended**
Environmental health	Pittsburgh working group
Safe housing	Pittsburgh working group
Navigation services	Pittsburgh working group
Improve access to oral health	Erie working group; Norristown working group; Harrisburg working group
Improve nutrition (reduce obesity and reduce food insecurity)	Norristown working group
Increase immunization rates	Norristown stakeholder
Adolescent Health: Proposed Priorities	**Venue where recommended**
Reduce substance use (e-cigarettes/vaping, opioids)	Erie and Harrisburg working groups; Norristown stakeholder
Improve nutrition (obesity/food security)	Norristown working group
Improve oral health	Harrisburg working group; Erie stakeholder
Increase social media safety	Pittsburgh stakeholder
Decrease social isolation	Scranton stakeholder
Increase HPV vaccinations	Norristown and Harrisburg stakeholder
Reduce STI rates	Harrisburg stakeholder
CSHCN: Proposed Priorities	**Venue where recommended**
Improve transportation services	Pittsburgh stakeholder
Improve oral health care	Norristown stakeholder
Improve access to home health care	Norristown stakeholder

SOURCE: Adapted from PA Title V Five-Year Needs and Capacity Assessment: Stakeholder Engagement in Prioritization, Wolfson et al. 2019.

Several priority areas that were not on the list that the BFH put forward for consideration and ranking were raised by stakeholders at the prioritization events held across the state. Table 9 lists all of the priorities that were proposed by stakeholders across the in-person prioritization events. Many of the priorities that were proposed can be broadly characterized as addressing social determinants of health – from deconstructing institutional racism, addressing social isolation, and ensuring safe housing to improving food security and transportation options. Priorities that address a social determinant of health were proposed across all prioritization meetings and for all of the Title V population domains. Another need that consistently emerged was improved oral health and access to oral health care in Pa. This proposed priority was suggested by at least one stakeholder for all of the Title V population domains. The need for improved access to and coordination of health care services was also frequently cited by stakeholders.

The BFH is committed to utilizing Title V funds responsibly to make meaningful change in the areas of need identified as being a high priority rather than overextending the funds in a way that might reduce overall efficacy. However, given the breadth of the priorities, the BFH is also committed to considering the extent to which the frequently cited needs may be addressed through the development and implementation of strategies over the next five-year cycle.

Selection of Final Priorities

Following the conclusion of the regional prioritization events and the agency meeting, the steering committee reviewed the priorities that were ranked highest by stakeholders at each of the events. Given that stakeholders were asked to make their rankings considering the values that had been identified at the start of the prioritization process, the data presented in the data briefs, and the unique needs in their networks of care, the BFH felt that the priorities that stakeholders had ranked in first place for each population domain should be considered as top priorities for the 2020 Title V MCHSBG cycle. However, the BFH also wanted to evaluate the capacity of the bureau to carry out work and programming related to those priorities prior to their final selection. This was achieved through evaluation of the bureau's existing capacity (described above) and review of the feedback received at the agency meeting. Once existing capacity or the ability to build capacity was confirmed, the first-ranked priority for each population domain was considered one of the final priorities.

Once all of the priorities that were ranked in first place were evaluated and ultimately selected as final priorities, the BFH considered those priorities that were ranked in second place in each domain and completed the same exercise of considering the capacity of the Bureau. Given that several of the priorities that had come in second place had tied, considerations related to capacity played a larger role in the final selection.

Once the BFH had a final draft of their proposed list of priorities for the 2020 Title V MCHSBG cycle, it was important to seek input from the DOH leadership, including Secretary Levine and her executive team, to again confirm that the priorities were consistent with the greater mission of the agency and that they could be feasibly addressed by the state's Title V program. As part of that process, the language in the priorities was adapted to say, "especially where there is inequity" rather than "especially among disparate populations." Health disparities are often defined as differences in health outcomes that occur among different population groups, whereas inequity refers to differences which are "systematic, unfair and avoidable" (Penman-Aguilar et al., 2016). The purpose of this change in language was to clarify that the focus would not be solely on populations that have "different" health outcomes but rather on populations and regions that are unfairly and unnecessarily experiencing adverse health outcomes. Secretary Levine also supported the addition of a seventh priority that explicitly addressed health equity, given the feedback received from stakeholders through the process about the importance of advancing health equity and addressing social determinants of health in Pa.

Below is a brief rationale for why each priority was selected as part of the final set of seven.

1. Reduce or improve maternal morbidity and mortality, especially where there is inequity

   This priority was ranked highest for the women/maternal health domain by stakeholders across regional prioritization events, other in-person events and the web survey. Stakeholders consistently reported that they viewed maternal mortality and morbidity to be a major issue for the state. Similarly, stakeholders engaged in focus groups, as part of the needs assessment indicated that support and services during and after pregnancy are important. Many stakeholders referred to the stark racial disparity in maternal mortality ratios and expressed a desire for more solutions that might help to address it. While maternal mortality rates may be decreasing in Pa., black and African American women were almost three times as likely to die a pregnancy-related death than white women from 2011-2015 (CDC, PMSS, 2011-2015).

Data on other health indicators related to maternal morbidity also suggest this is an area of need in Pa. The rate of severe maternal morbidity per 10,000 delivery hospitalizations has increased in Pa. from 85.8 women with severe morbidity per 10,000 delivery hospitalizations in 2010 to 114.8 in 2015 (Health care Cost and Utilization Project – PA State Inpatient Database, 2010-2015). Maternal morbidity is also most apparent among minority women, especially among non-Hispanic black women. There is also still an opportunity to improve related protective factors during and after pregnancy, such as receipt of prenatal care. From 2015 to 2017, approximately 1.6% of women in Pa. did not have any prenatal care, and 26.2% of women in Pa. did not receive timely prenatal care (PA Birth Certificate Data, 2012-2017). Again, black and African American women were least likely to receive prenatal care as compared to women of another race or ethnicity.

Stakeholders also indicated that, while awareness of maternal mortality is increasing, the severity of the issue is only becoming more apparent as data collection and reporting improve. In Pa., improvements to data quality and review of maternal deaths are ongoing. Pa.'s Maternal Mortality Review Committee (MMRC) was established in 2018 with the goal to systematically review all maternal deaths, identify root causes of these deaths, and develop strategies to reduce preventable morbidity, mortality, and racial disparities related to pregnancy in Pa. Given its recent inception, recommendations from the MMRC have not yet been released. However, it became apparent through discussion with agency partners at the capacity meeting that the recommendations from their forthcoming report could be used to guide the direction of Title V's work.

2. Reduce rates of infant mortality (all causes), especially where there is inequity

This priority was ranked highest for the infant/perinatal health domain by stakeholders across regional prioritization events, other in-person events, and the web survey. While stakeholders felt that community members may not view infant mortality as a widespread concern unless they have been personally affected, they indicated that, among providers and public health professionals, infant mortality is recognized as an issue of high severity and importance. In particular, stakeholders emphasized the stark disparity in mortality rates between white and black or African American infants in Pa.

The infant mortality gap between black and white infants in Pa. persists. Since 2012, the infant mortality rate in Pa. has decreased from 7.0 deaths per 1,000 live births to 6.1 infant deaths per 1,000 live births in 2016, nearly meeting the 2020 goal of 6.0 deaths. However, the infant mortality rate for black/African American infants is 14.6 deaths per 1,000 live births, which is two times higher than the overall state rate, six times higher than the mortality rate for

Asian/Pacific Islander infants (2.3) and three times higher than the rate for white infants (4.6) [PA Death Certificate Dataset, 2012-2016].

Many stakeholders also indicated that this priority is intertwined with preterm birth and maternal well-being, suggesting that work on this priority may impact other areas of maternal and perinatal health.

3. Improve mental health, behavioral health and developmental outcomes for children and youth with and without special health care needs

This priority was ranked highest for the child and adolescent health domains by stakeholders across regional prioritization events, other in-person events, and the web survey. This priority was also ranked in second place for CSHCN by stakeholders.

Stakeholders indicated that the mental health needs of children are not being sufficiently addressed and that addressing this priority will also have positive implications for bullying, which is known to be an issue among young children. Similarly, stakeholders reported that increased support of mental health and behavioral health services among adolescents is warranted in Pa. and could lead to overall improvement in adolescent health and in the transition from adolescence to adulthood. Among adolescents, stakeholders reported that there is a need for more culturally competent care and care professionals that provide care for LGBTQ adolescents. Among CSHCN stakeholders, many indicated that there is a gap in the provision of and access to behavioral and mental health services among the CSHCN population. There was consensus among stakeholders that there is a growing awareness about mental health issues and stigma is decreasing, making programming or related activities more acceptable to the community. Youth and their providers who engaged in focus group discussions as part of the needs assessment also indicated that mental and behavioral health services are important in Pa.

Similarly, conversations at the agency meeting suggested that Title V work in this area could serve to fill existing gaps in the provision of mental and behavioral services. The BFH has some existing capacity in this area as it currently administers programming related to adolescent health that could be expanded to include children.

4. Improve the percent of children and youth with special health care needs who receive care in a well-functioning system

This priority was ranked highest for the CSHCN health domain by stakeholders across regional prioritization events, other in-person events, and the web survey. Stakeholders reported that improving access to a well-functioning system is viewed as a large concern by the community because there are not enough specialists and there is a lack of communication across systems. Similar sentiments emerged from the focus group discussions held with families, providers, and children and youth with special health care needs as part of the needs assessment. Many of the major themes that emerged from those discussions (i.e., doctor turnover, lack of continuity of care, transition services, caregiver respite) are related to a well-functioning system of care.

Stakeholders felt strongly that a well-functioning system should provide culturally competent care and reported that, even when services exist, the system may be too cumbersome for families to navigate. Again, this is consistent with ideas expressed during the focus groups, namely that discrimination is experienced during receipt of health care and improved care navigation services are needed. Transportation was also consistently described as a major barrier to a well-functioning system for many families at the prioritization events and through focus group discussions. Many stakeholders who ranked this priority highest indicated that they did so in part because success in establishing a well-functioning system could also serve to improve transition services and access to behavioral and mental health care.

As of 2017, there are an estimated 511,324 children age zero to17 in Pa. living with one or more special health care needs, which is 19.1% of Pa. children. Of these 511,324 children and youth, only 16.5% report receiving care in a well-functioning system. This is lower than the percentage of children without special health care needs (23.3%). Pa. has not met the HP2020 goal of increasing the percentage of CSHCN who receive care in a well-functioning system to 22.4% for children age 0 to 11 and to 15.1% of children age 12 to 17 (NSCH, 2016-2017). Having a well-functioning system of care is imperative to optimizing the physical, mental, and behavioral health of Pa.'s CSHCN. Attempting to navigate a fragmented system can affect the health and well-being of both CSHCN and their families/caregivers.

5. Reduce rates of child mortality and injury, especially where there is inequity

   This priority was ranked in second place for the child health domain by stakeholders across regional prioritization events, other in-person events, and the web survey. According to HRSA, children are between the ages of 1 and 21, and all children within that age bracket are encompassed within this priority. Stakeholders across events indicated that this priority is highly linked with the mental health/behavioral health priority. Stakeholders commented that data trends suggest that non-fatal injuries and related mortality rates are prevalent and a high severity issue, especially for youth and adolescents. In Pennsylvania, the leading causes of child and adolescent death include accidents, injuries and unintentional harm, as well as suicide and intentional harm. Youth suicide rates have consistently increased over the past several years. The suicide rate among adolescents aged 15 to 19 years old was 9.5 deaths per 100,000 in 2016 – an increase from 2012 when the youth suicide rate in Pa. was 6.7 adolescent deaths per 100,000 (ODPHP, 2020; DOH, Death Certificate Data, 2012-2016). In order to address increasing rates of suicide, Governor Wolf's administration recently convened a suicide prevention task force. Following a series of listening sessions held statewide that engaged over 800 Pennsylvanians, the task force indicated that suicide prevention strategies for school-aged youth and young adults are needed and desired (PA DHS, 2020). That recommendation is consistent with the themes that Title V stakeholders brought forward throughout the Title V needs assessment. Title V stakeholders also indicated that child and adolescent mortality prevention strategies could be policy-focused rather than solely programmatic.

Several areas of concern that stakeholders identified when discussing child injury were improving school safety, safety in the home, improving firearm safety, and focusing on environmental health. While not all injuries result in death, non-fatal injuries that require hospitalization can develop into long-term health issues. According to HCUP data from state inpatient databases, the rate of hospitalization for non-fatal injury per 100,000 children aged 0 to 9 in Pa. decreased from 185.6 in 2011 to 153.4 in 2014. However, Pennsylvania still exceeds the national rate of non-fatal injury. In Pennsylvania, experiences with violence and hazards in the home contribute to the non-fatal injury hospitalization rate. Pennsylvania's diverse landscape of rural and urban communities includes some of the oldest housing in the nation, and indoor environmental health and safety hazards, such as lead, tend to be found disproportionately in older and substandard housing. Environmental health hazards and safety in the home were commonly cited as important by stakeholders throughout the needs and capacity assessment.

6. Strengthen Title V staff's capacity for data-driven and evidence-based decision making and program development

This priority embodies the BFH's commitment to ensuring that all Title V work, programming, and activities are data-driven and evidence-based This priority is a continuation of the data-focused priority that was included in Pa.'s state action plan during the former Title V MCHSBG cycle ("Title V staff and grantees identify, collect and use relevant data to inform decision-making and evaluate population and programmatic needs").

While the BFH has some program staff that consistently collect and use data for program evaluation and decision-making, the 2015 Needs and Capacity Assessment revealed that there are not consistent practices in place across the BFH or among grantees. To systematically address this, the BFH developed objectives and strategies to build capacity similar to the way objectives and strategies are created to serve population needs.

While progress was made in building staff capacity to make decisions and develop programs based on data and evidence during the last block grant cycle, internal surveys of BFH staff conducted as part of the internal capacity assessment in 2020 suggest that continued training in these topic areas is still warranted and desired. Additionally, given the high percentage of new BFH staff at the programmatic level, continued training and opportunities for professional development in this area may benefit staff who have worked in public health but are new to Title V and public health programming. Similarly, with the adoption of this priority, the BFH also intends to continue building capacity among grantees who administer Title V-funded programs across the state. While grantees indicated in the 2018 interim needs assessment that they had built capacity that would allow them to identify evidence-based practices, some indicated that additional technical assistance is needed to access data and effectively evaluate their programs.

7. **7.** Support and effect change at the organizational and system level by supporting and promoting policies, programs, and actions that advance health equity, address the social, environmental, and economic determinants of health, and deconstruct institutionalized systems of oppression

   The framework of the Title V Needs and Capacity Assessment for 2020 was health equity. This framework was identified based on the results of the 2015 Needs and Capacity Assessment which suggested that progress on maternal and child health in Pa. cannot be made until all Pennsylvanians can attain health and wellness by addressing societal barriers and the disproportionate burden of illness, disease, and mortality. The importance of advancing health equity and addressing social determinants of health was reiterated by stakeholders across regional prioritization events. During the discussion of values that took place at the start of each prioritization meeting, multiple stakeholders commented that the value related to equity should be weighted more heavily given the stark disparities across many indicators of health in Pa.

   Additionally, social determinants of health were a common theme that emerged throughout the 2020 Needs and Capacity Assessment. Through focus group discussions, experiences with discrimination while seeking health care services were cited frequently and emerged as a major theme across population domains. Results of the web-based survey that was conducted to gather primary data during the data analysis phase demonstrated that many of the factors that both health providers and service recipients identified as affecting health in their families, communities, and networks of care were social, economic, or environmental determinants of health. Similarly, many of the priorities that were proposed by stakeholders during the prioritization events were related to social determinants of health.

   Given that there are many factors external to the health care system that have a direct influence on the health outcomes of MCH populations in Pa., this priority was created in response to stakeholder feedback in order to make the BFH's commitment to advancing health equity and addressing the social determinants of health explicit and to promote the development of innovative, systems-level strategies.

The BFH developed and implemented a prioritization process that was transparent and deliberately committed to incorporating the input of stakeholders and the needs of their communities. As such, it was important to the BFH that the input and rankings received from stakeholders across Pa. directly informed the selection of the final priorities. The final set of seven priorities are responsive to the high priority needs identified over the course of the assessment and are listed in their final form in the subsequent section.

Title V Maternal and Child Health Services Block Grant Priorities: 2021-2025

The BFH will use Title V funds over the next five-year funding cycle to develop and implement strategies informed by the following seven priorities:

1. **1.** Reduce or improve maternal morbidity and mortality, especially where there is inequity;
2. **2.** Reduce rates of infant mortality (all causes), especially where there is inequity;

3. Improve mental health, behavioral health and developmental outcomes for children and youth with and without special health care needs;
4. Improve the percent of children and youth with special health care needs who receive care in a well-functioning system;
5. Reduce rates of child mortality and injury, especially where there is inequity;
6. Strengthen Title V staff's capacity for data-driven and evidence-based decision making and program development; and
7. Support and effect change at the organizational and system level by supporting and promoting policies, programs and actions that advance health equity, address the social, environmental and economic determinants of health and deconstruct institutionalized systems of oppression.

Next Steps

Dissemination of Final Priorities

Once finalized, the new priorities were distributed to all stakeholders on the Title V email distribution list, including those who attended one of the regional prioritization meetings, participated in an in-person event, or completed the web survey. The document circulated (included in the Appendix, Supplement M), briefly describes how the priorities were identified and how they will be utilized to develop strategies for the next Title V funding cycle from 2021 to 2025. The document has also been posted on Pa.'s Title V website and will continue to be distributed at in-person meetings and via social media.

Action Planning and Development of Strategies and Measures

The new priorities will inform the development of Pa.'s new Title V five-year action plan. Component parts of the action planning phase include selection of NPMs and NOMs, development of state performance measures (SPMs) as needed, development of evidence-based strategy measures (ESMs) and development of performance and process objectives that will be used to evaluate progress made over the course of the five-year period.

Conclusion

The 2020 Title V Five-Year Needs and Capacity Assessment was successful and allowed the state Title V program to identify priorities that are representative of the areas of greatest need among the maternal and child health populations in Pennsylvania in collaboration with stakeholders and service recipients. However, given that the public health needs of Pennsylvania and its maternal and child health populations are dynamic, their needs and the Title V program's efficacy in meeting them will be continually assessed over the course of this funding cycle.

Additionally, while the needs and capacity assessment did achieve the goals established at the start of the process, it was not without challenges. These challenges and opportunities for improvement are described below.

Challenges and Lessons Learned: Preparing for 2025

One challenge of the needs and capacity assessment was procuring the data needed to comprehensively characterize the health status of the MCH populations in Pa. In particular, it was challenging to evaluate the health status of CSHCN. The NSCH is the primary dataset available that includes indicators specific to CSHCN. However, due to the small sample size, it was not possible to evaluate disparities or stratify by demographic variables – most of the comparisons were made between children with and without special health care needs. Additionally, many of the indicators related to behavioral and mental health which can be characterized for adolescents using the YRBSS, cannot be characterized among CSHCN in the same age group. Given consistent reports from stakeholders and providers in Pa. that services related to behavioral and mental health are needed among this population, the lack of an adequate data source to monitor change at a state or national level is problematic.

Another challenge was engaging service recipients, family members and caregivers – especially in the prioritization process. Few service recipients attended the in-person regional prioritization events regardless of efforts to seek their input on scheduling. Additionally, while the response to the web surveys was robust compared to previous surveys conducted by the BFH, the demographics of the respondents suggest that the survey did not reach minority communities and those of low socioeconomic status. Conversely, focus groups aimed at gathering qualitative data were successful in generating meaningful dialogue about health needs with service recipients. The focus groups were hosted by providers and associated costs, including meals, transportation, child care, and monetary incentives for participants, were reimbursed by the BFH. This may suggest that more concerted efforts are needed to engage stakeholders in events that are hosted by the BFH. Several possible options to consider for the future include coordinating with providers to offer transportation to in-person events, exploring childcare options, better advertising of incentives (such as meals), and consideration of additional monetary incentives for participation. Another possibility would be holding a meeting that is conference call or Skype-based, so that families or service recipients who are unable to attend in person can still participate.

The BFH also received feedback from providers that additional coordination between state agencies conducting needs assessments is warranted to prevent survey fatigue, especially when the target MCH population is the same.

Given that the Title V MCHSBG requires that a Needs and Capacity Assessment be completed at the end of each five-year cycle, the lessons learned from this assessment will inform the development of the next Title V Five-Year Needs and Capacity Assessment in 2025.

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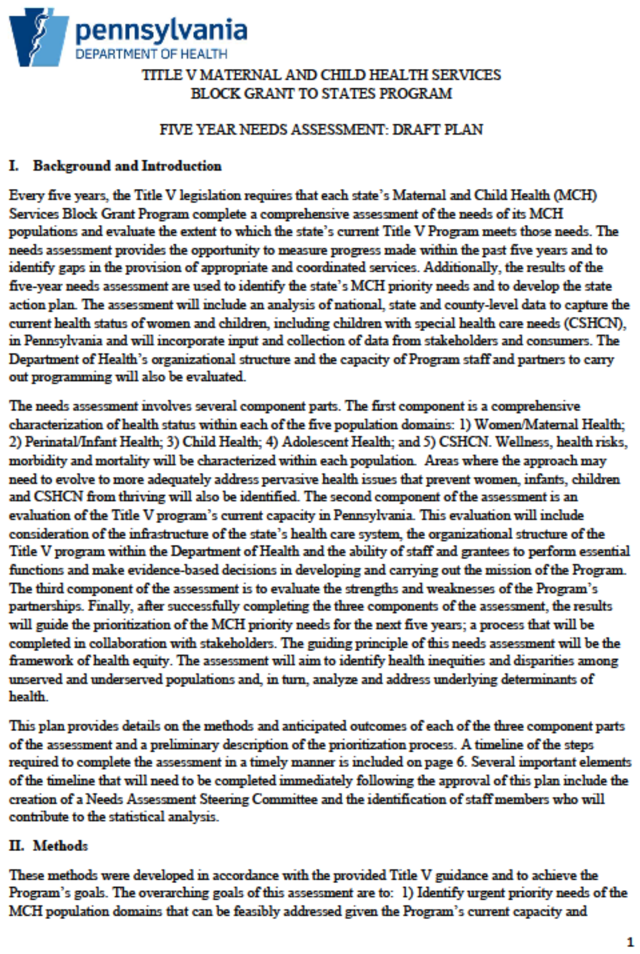
Appendix

Supplement A – Title V Five-Year Needs and Capacity Assessment Plan



pennsylvania
DEPARTMENT OF HEALTH

TITLE V MATERNAL AND CHILD HEALTH SERVICES
BLOCK GRANT TO STATES PROGRAM

FIVE YEAR NEEDS ASSESSMENT: DRAFT PLAN

I. Background and Introduction

Every five years, the Title V legislation requires that each state's Maternal and Child Health (MCH) Services Block Grant Program complete a comprehensive assessment of the needs of its MCH populations and evaluate the extent to which the state's current Title V Program meets those needs. The needs assessment provides the opportunity to measure progress made within the past five years and to identify gaps in the provision of appropriate and coordinated services. Additionally, the results of the five-year needs assessment are used to identify the state's MCH priority needs and to develop the state action plan. The assessment will include an analysis of national, state and county-level data to capture the current health status of women and children, including children with special health care needs (CSHCN), in Pennsylvania and will incorporate input and collection of data from stakeholders and consumers. The Department of Health's organizational structure and the capacity of Program staff and partners to carry out programming will also be evaluated.

The needs assessment involves several component parts. The first component is a comprehensive characterization of health status within each of the five population domains: 1) Women/Maternal Health; 2) Perinatal/Infant Health; 3) Child Health; 4) Adolescent Health; and 5) CSHCN. Wellness, health risks, morbidity and mortality will be characterized within each population. Areas where the approach may need to evolve to more adequately address pervasive health issues that prevent women, infants, children and CSHCN from thriving will also be identified. The second component of the assessment is an evaluation of the Title V program's current capacity in Pennsylvania. This evaluation will include consideration of the infrastructure of the state's health care system, the organizational structure of the Title V program within the Department of Health and the ability of staff and grantees to perform essential functions and make evidence-based decisions in developing and carrying out the mission of the Program. The third component of the assessment is to evaluate the strengths and weaknesses of the Program's partnerships. Finally, after successfully completing the three components of the assessment, the results will guide the prioritization of the MCH priority needs for the next five years; a process that will be completed in collaboration with stakeholders. The guiding principle of this needs assessment will be the framework of health equity. The assessment will aim to identify health inequities and disparities among unserved and underserved populations and, in turn, analyze and address underlying determinants of health.

This plan provides details on the methods and anticipated outcomes of each of the three component parts of the assessment and a preliminary description of the prioritization process. A timeline of the steps required to complete the assessment in a timely manner is included on page 6. Several important elements of the timeline that will need to be completed immediately following the approval of this plan include the creation of a Needs Assessment Steering Committee and the identification of staff members who will contribute to the statistical analysis.

II. Methods

These methods were developed in accordance with the provided Title V guidance and to achieve the Program's goals. The overarching goals of this assessment are to: 1) Identify urgent priority needs of the MCH population domains that can be feasibly addressed given the Program's current capacity and

1

Note: Please double click on the image to view the complete supplement.

Supplement B – Title V Five-Year Needs and Capacity Assessment: Overview and Timeline

pennsylvania
DEPARTMENT OF HEALTH

TITLE V FIVE YEAR NEEDS & CAPACITY ASSESSMENT

WHAT IS THE PURPOSE OF THE TITLE V NEEDS & CAPACITY ASSESSMENT?

Every five years, Pennsylvania's Maternal and Child Health (MCH) Services Title V Block Grant requires that the Bureau of Family Health conduct a state-level, comprehensive assessment of the health status of women, children, adolescents and children and youth with special health care needs in Pennsylvania to identify priority health needs and to guide state and local public health work. During this assessment, the Bureau of Family Health also evaluates its capacity to serve the MCH populations.

The guiding principle of the 2020 needs assessment is health equity. Health equity is achieved when all people can attain health and wellness. As such, the goal of this assessment is to analyze data and gather information from stakeholders to characterize the health issues facing the MCH populations. This assessment also aims to identify specific groups that cannot attain health and wellness because they are unduly underserved and/or are disproportionately affected by illness, disease or mortality. Underlying determinants of health such as social, economic or environmental factors or disadvantages will also be analyzed and addressed. The results from the assessment will be used to identify seven to 10 specific priorities that can be positively impacted by strategic public health work over the next five years (2021 to 2025). State and local Title V staff will use the selected priorities to focus efforts, align resources and make a positive impact on the health of the MCH populations.

WHAT ARE THE COMPONENTS OF OUR NEEDS ASSESSMENT?

The needs and capacity assessment is a multi-step process made up of many component parts. Preparation for the assessment includes reviewing the guidance provided by HRSA's Maternal and Child Health Bureau, assembling an internal needs assessment steering committee and developing the assessment timeline, guiding principle(s) and work plan.

The next step includes collecting and analyzing quantitative and qualitative data to assess health status and to evaluate the Title V program's current capacity. Results from the quantitative and qualitative data collection and from the capacity assessment will then be utilized to identify priority health needs that can be feasibly addressed by the Title V Program. Stakeholder input is sought at various times throughout the assessment and is critical to informing the final prioritization of the MCH health needs that will be addressed over the next five years.

HOW DOES THE NEEDS & CAPACITY ASSESSMENT AFFECT ME?

The seven to 10 priorities that are selected through the needs assessment process will be incorporated into the State Action Plan and will drive the issues state and local Title V programs, staff and grantees address over the next five years (2021-2025). Maternal and child health professionals and Title V staff will develop and implement programs and strategies that aim to address these priorities. The goal is to promote and improve the health and well-being of women, children, adolescents, children and youth with special health care needs and their families.

Bureau of Family Health
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Rev. April 25, 2019

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Supplement C – List of Datasets and Indicators Evaluated; Limitations of Datasets

Supplement C Table: Datasets and Indicators Evaluated

Dataset	Years	Indicator Description
American Community Survey, 1-Year Estimate (Pennsylvania and National Data)	2015-2016	Percent of children ages 0 through 17 without health insurance
Behavioral Risk Factor Survey (Pennsylvania and National Data)	2011-2017	Percent of women ages 18 through 44 with a preventive medical visit in the past year – Well Woman Visit
Behavioral Risk Factor Survey (Pennsylvania and National Data)	2011-2017	Percent of women who smoke during pregnancy
CDC Wonder, Detailed Mortality Dataset (Pennsylvania and National Data)	2012-2016	Pre-term related mortality rate per 100,000 live births
CDC Wonder, Detailed Mortality Dataset (Pennsylvania and National Data)	2012-2017	Child mortality rate per 100,000
CDC Wonder, Linked Birth/Infant Death Records Dataset (Pennsylvania and National Data)	2012-2016	Rate of infant deaths related to birth defects
National Center for Fatality Review and Prevention - National Reporting System (Pennsylvania Data)	2011-2015	Percentage of total child deaths reviewed by Child Death Review teams
National Center for Fatality Review and Prevention - National Reporting System (Pennsylvania Data)	2011-2015	Percentage of total child deaths attributed to external causes that were reviewed
National Center for Fatality Review and Prevention - National Reporting System (Pennsylvania Data)	2015	Percentage of total child deaths attributed to sudden unexpected infant death that were reviewed
National Immunization Survey-Child (Pennsylvania and National Data)	2016-2017	Percentage of infants breastfed exclusively through 3 and 6 months
National Immunization Survey-Child, ChildVaxView (Pennsylvania and National Data)	2015-2017	Percentage of children, ages 19 through 35 months, who completed the combined 7-vaccine series

Dataset	Years	Indicator Description
National Immunization Survey-Flu, FluVaxView (Pennsylvania and National Data)	2014-2018	Percentage of children, ages 6 months through 17 years who are vaccinated annually against seasonal influenza
National Immunization Survey-Teen, TeenVaxView (Pennsylvania and National Data)	2015-2017	Percent of adolescents, age 13 through 17, who have received at least one dose of the HPV vaccine
National Immunization Survey-Teen, TeenVaxView (Pennsylvania and National Data)	2015-2017	Percent of adolescents, ages 13 through 17, who have received at least one dose of Tdap vaccine
National Immunization Survey-Teen, TeenVaxView (Pennsylvania and National Data)	2015-2017	Percent of adolescents ages 13 through 17, who have received at least one dose of the meningococcal conjugate vaccine
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percentage and count of children ages 9 to 35 months who received a developmental screening using a parent-completed tool
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children, ages 0 through 17, in excellent or very good health
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children ages 6 through 11 who are physically active at least 60 minutes per day
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children who have had a child well-visit
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children ages 3 through 17 with a mental/behavioral condition who receive treatment or counseling
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children ages 1 through 17 who had a preventive dental visit in the past year
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children aged 0 through 17 who are adequately insured

Dataset	**Years**	**Indicator Description**
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of parents who received specific information concerning their child from a doctor or other health care provider
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children who have experienced bullying (aged 6-17)
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children who live in households where someone smokes
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children, ages 1 through 17, who have decayed teeth or cavities in the past year
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of children, ages 2 through 4, and adolescents, ages 10 through 17, who are obese (BMI at or above the 95th percentile)
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of parents who report their child experiencing at least one ACE (ages 0 to 12)
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percentage of children with ADHD who received behavioral treatment within the past 12 months
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percentage of children ages 0 through 17 who receive care in a well-functioning system
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percentage of children with and without special health care needs, ages 0 through 17, who have a medical home
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of adolescents with and without SHCN who received services to make transition to adult care
National Survey of Children's Health (Pennsylvania and National Data)	2016	Percent of children with special health care needs ages 0 through 17
National Survey of Children's Health (Pennsylvania and National Data)	2016	Percent of children ages 3 through 17 diagnosed with an autism spectrum disorder

Dataset	Years	Indicator Description
National Survey of Children's Health (Pennsylvania and National Data)	2016	Percent of children, ages 3 through 17, diagnosed with ADD/ADHD
National Survey of Children's Health (Pennsylvania and National Data)	2016-2017 combined	Percent of CSHCN with inadequate access to needed health care within the last 12 months
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percentage of women who receive early, adequate or no prenatal care
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women who attend a postpartum care visit following birth
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women delivering a live birth who used contraception postpartum
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women delivering a live birth who report having discussed preconception health behaviors with a health care worker prior to pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women delivering a live birth who reported taking a multivitamin or folic acid-containing vitamin prior to pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women with dental visit during pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women who smoked during the third trimester of pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percentage of women who report alcohol consumption during the third trimester of pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women who attain a recommended weight based on their pre-pregnancy weight/BMI

Dataset	Years	Indicator Description
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women reporting a live birth who had a healthy weight prior to pregnancy
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women who reported intimate partner violence by current or former partner
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women with gestational diabetes
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of women with hypertension
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percentage of women who reported depression during most recent pregnancy; percentage of women who reported depression that sought help from a health professional
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of infants ever breastfed
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of infants placed to sleep on their backs
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of infants placed to sleep on a separate approved sleep surface
PRAMS (Pennsylvania and Aggregate Data)	Phase 7, 2012-2015	Percent of infants placed to sleep without loose objects or bedding
PRAMS (Pennsylvania and Aggregate Data)	Phase 8	Percent of women who reported use of marijuana or anti-depressants or prescription pain relievers during pregnancy
Pennsylvania Birth Certificate Dataset	2013-2017	Percent of women with gestational diabetes
Pennsylvania Birth Certificate Dataset	2013-2017	Percent of women with gestational hypertension

Dataset	Years	Indicator Description
Pennsylvania Birth Certificate Dataset	2013-2017	Percent of women who smoked during pregnancy
Pennsylvania Birth Certificate Dataset	2013-2017	Percentage of C-sections among low risk first births
Pennsylvania Birth Certificate Dataset (EDDIE)	2012-2016	Percentage of women who receive prenatal care beginning in the first trimester
Pennsylvania Birth Certificate Dataset (EDDIE)	2012-2016	Percentage of low and very low birthweight deliveries
Pennsylvania Birth Certificate Dataset (EDDIE)	2012-2016	Percentage of pre-term births
Pennsylvania Birth Certificate Dataset (EDDIE)	2012-2016	Percentage of infants ever breastfed
Pennsylvania Birth Certificate Dataset (EDDIE)	2012-2016	Pregnancy rate among adolescents aged 15 to 17
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Perinatal mortality rate per 1,000 live births plus fetal deaths
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Neonatal mortality rate per 1,000 live births
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Infant mortality rate per 1,000 live births
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Post neonatal mortality rate per 1,000 live births
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Sudden infant death syndrome (SIDS) rate per 1,000 live births
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Adolescent mortality rate among youth ages 10 through 19 per 100,000
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Adolescent motor vehicle mortality rate ages 15 through 19, per 100,000
Pennsylvania Death Certificate Dataset (EDDIE)	2012-2016	Adolescent suicide rate, ages 15 through 19, per 100,000
Pennsylvania Department of Health, Keystone 10 data	2016-2018	Of the total number of hospitals and birthing centers in Pa., percentage that are participating in the Keystone 10 Initiative

Dataset	**Years**	**Indicator Description**
Pennsylvania Department of Health, Keystone 10 data	2016-2018	Average number of K10 steps completed by participating facilities
Pennsylvania Department of Health, Newborn Screening data	2017-2018	Percentage of newborns screened per total live births
Pennsylvania Department of Health, Newborn Screening data	2017-2018	Percent of newborns screened for a heritable disorder with on time physician notification for out of range screening who receive follow-up
Pennsylvania Department of Health, Newborn Screening data	2017-2018	Average time from collection of specimen/birth to report out
Pennsylvania Department of Health, Newborn Screening data	2017-2018	Percentage of non-time critical and time critical disorder reports that are made within the recommended time period
Pennsylvania Health Care Cost Containment Council	2011-2017	Rate of hospitalization for non-fatal injury per 100,000 children, ages 0 through 9 and 10 to 19
Pennsylvania Health Care Cost Containment Council (PA Open Data)	SFY 2008 - SFY 2017	Rate of infants born with neonatal abstinence syndrome per 1,000 hospital births
Pennsylvania Youth Survey	2013, 2015, 2017	Percent of adolescents who report that they could ask their parents for help with a personal problem
Pennsylvania Youth Survey	2013, 2015, 2017	Percentage of adolescents who have used prescription pain relievers without a doctor's orders
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents 12 through 17 who are physically active at least 60 minutes per day

Dataset	Years	Indicator Description
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents who did not use both a condom during last sexual intercourse and birth control pills, an IUD, or implant, or shot, or birth control ring before last sexual intercourse
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents who report being in a physical fight within the past 12 months
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents who report experiencing sexual violence
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents aged 12 through 17 who are bullied or who bully others
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents who report smoking cigarettes within the past 30 days
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percent of adolescents who report drinking alcohol within the past 30 days
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percentage of adolescents who reported feeling sad or hopeless within the past 12 months (almost every day for two weeks or more in a row so that they stopped doing some usual activities, during the 12 months before the survey)
Youth Risk Behavior Survey (Pennsylvania and National data)	2009, 2015, 2017	Percentage of adolescents who reported suicidal ideation within the past 12 months
Pregnancy Mortality Surveillance System (PMSS) (Pennsylvania data)	2011-2015	Rate of pregnancy-related maternal mortality per 100,000 live births

Limitations

Given that the data presented in this report were pulled from multiple datasets, data presentation and the variables available for stratification vary by dataset. Whenever possible, a 95% confidence interval reflecting the amount of random error in the sample is presented for each point estimate. The 95% confidence intervals should be referenced to inform interpretation of the data presented. Given that most of the data presented were accessed using interactive data queries available online, additional comparative analyses were often not feasible and measures of statistical significance (i.e., p-values) are not presented.

Limitations by Dataset

CDC Wonder

The most recent data available as of January 2019 when analysis was completed were from 2017 (or 2016 for certain indicators). Additionally, the online query system often provides crude rates only and prevents age-adjusted rates when grouping by age. Changes in cause of death classification from ICD-9 to ICD-10 codes in the final quarter of 2015 may affect reporting trends in subsequent years and make comparison across years before and after 2015 inaccurate (CDC, CDC Wonder, 2012-2017).

EDDIE

The Enterprise Data Dissemination Informatics Exchange (EDDIE) is an interactive web tool that summarizes health indicators in Pennsylvania. These data are provided by the Division of Health Informatics, Pennsylvania Department of Health. Regional or county-level analysis was limited for some health indicators as data was suppressed to maintain confidentiality due to low numbers.

National Center for Fatality Review and Preventions – Case Reporting System (NCRFP-CRS)

The data used for the present analysis of reviewed child deaths were from the National Center for Fatality Review and Preventions National Reporting System. Pennsylvania local CDR teams enter data from reviews directly into the web-based data system. The data is then downloaded from the website for analysis. Given that reviews are triggered by the filing of death certificates, the information available on death certificates may affect the review process through any limitations associated with the accuracy and reliability of the information presented on death certificates. While some review cases are initiated, not all the fields of information, or components, are completed during the review or by the time of this report. Data entry into NCFRP-CRS is dependent upon local teams' ability to identify staff to complete modules. Discussion or findings during reviews that are not entered in NCFRP-CRS or other reports completed by local teams are not included. For these reasons, it is important to recognize that frequencies and percentages based on available review data should be applied cautiously in drawing inferences on total deaths statewide.

Additionally, when evaluating reviewed deaths attributed to SUID, only data from 2015 or later was considered; Pennsylvania joined the SUID registry in 2015 and infant death review data for SUID prior to that is considered incomplete.

National Immunization Survey (NIS)

The National Immunization Survey-Teen (NIS-Teen) and National Immunization Survey-Child (NIS-Child) are composed of: (1) a household telephone survey designed to capture information about routine and; (2) a mail survey to health care providers (allowing for validation of parent/guardian self-report using an immunization record). NIS-Child captures information on children aged 19 to 35 months, while NIS-Teen captures information on adolescents aged 13 to 17 years. Although the results of both surveys are weighted to be representative, given the small state-based sample size and the possibility of incomplete records, results should be interpreted with caution (CDC, December 2018).

The National Immunization Survey-Flu captures seasonal influenza vaccination information for children aged 6 months to 17 years via telephone survey (NIS-Flu). Research demonstrates that, given that flu vaccination status was ascertained via parental report and not validated with medical records, the results are subject to recall bias (Brown et al. 2011; CDC, October 2018). For example, a recent study of children aged 6 to 23 indicated that provider reports of flu vaccination were 12 to 17 percentage points lower than the parent-reported estimates found on FluVaxView for the 2010-11 and 2012-13 flu seasons (Santibanez et al. 2016; CDC, October 2018). Another possible source of bias is a high nonresponse rate for NIS-Flu. Comparison of vaccination rates across seasons may be challenging if parental reporting is inaccurate or as a result of inconsistent non-response rates (CDC, October 2018). Although incomplete provider records or failure to report may influence provider accuracy, NIS-Flu likely overestimates vaccination coverage. Finally, the national estimates from NIS-Flu exclude U.S. territories (CDC, October 2018).

A limitation of all NIS surveys is that phoneless households are not sampled – suggesting that the overall sample may be subject to selection bias (CDC, December 2018).

National Survey of Children’s Health (NSCH)

The NSCH surveys a sample of U.S. households with children regarding child health and well-being. The survey is designed to provide representative state and national estimates for non-institutionalized children aged 0 to 17 ((DRCCAH, 2016-2017). At the time of analysis, only 2016 data and a combined 2016-2017 dataset were available via the interactive data query available from the Data Resource Center for Child & Adolescent Health. Additionally, the sample weighting was updated in 2016, making it impossible to compare data between 2016 and prior years (i.e., 2011). As such, it was not possible to analyze state trends over time and the focus of analysis of this dataset was comparison between state and national data, primarily using the combined two-year dataset (2016-2017).

The NSCH is the HRSA-recommended dataset for many CSHCN health indicators, as it provides both national and state-level data on a representative sample of children and youth with special health care needs. According to the NSCH, “CSHCN status is determined using a validated instrument for identification of children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer.” (DRCCAH, 2016-2017). However, due to the small sample size, it was not possible to stratify within the CSHCN sub-group to evaluate disparities.

Newborn Screening Database

The number of infants screened annually by the Newborn Screening and Genetics (NSG) Program can include infants who reside out of state but are born in Pennsylvania as well as all infants who receive Pa. birth certificates (mother is a Pa. resident). However, the number of live births that occur in Pennsylvania annually is constructed using exclusively Pa. birth certificate files. For the purpose of the present analysis, two numbers were available for total live births in Pennsylvania: 1) the number of infants born to Pa.-resident mothers in Pennsylvania who received a birth certificate; and 2) the number of infants born to Pa.– resident mothers in Pennsylvania **and** outside of Pennsylvania who received a birth certificate. Neither of those two numbers include non-resident infants born in Pennsylvania – infants that would be eligible for screening by the NSG program but that would not receive a birth certificate. As such, calculating a proportion of infants screened from the total live births data available from birth certificates is imperfect – non-Pa. resident infants born in Pa. who were screened but did not receive a birth certificate would not be represented in the denominator. Similarly, when analyzing the percentage of infants screened by county in 2017, there were several limitations. The numerator, which represents newborns screened by county, was divided by the denominator, which is newborns registered for a birth certificate in that county. The numerator might exclude parents who reside in those counties, but whose baby was not born in the county. Conversely, the denominator might include newborns born out of state whose parents reside in those counties. Newborns whose mother's resident county is outside of Pa. (totaling 2,565 newborns for 2017) were excluded from newborn screening county analysis.

Additionally, prior to 2018, there was no way to account for how many infants with Pa. birth certificates had received screening. As of 2018, birth certificate records and newborn screening records are now matched, allowing for a more accurate calculation of the percentage of Pa. infants with birth certificates that were screened in the future.

Pennsylvania Health Care Cost Containment Council (PHC4)

Given the focus of this entity is cost containment throughout the health care sector, data is often presented by state fiscal year rather than by calendar year. As a result, annual calendar-year data available nationally is not directly comparable to data presented by state fiscal year. This was the case for the neonatal abstinence syndrome data given that state incidence rates from PHC4 were presented as two-year estimates from state fiscal year 2009 to 2017, whereas national incidence rates are annual calendar year estimates from 2009-2012.

Additionally, for non-fatal injury hospitalization data from PHC4, morbidity codes changed from ICD-09-CM to ICD-10-CM in the fourth quarter of 2015. Although ICD-10 codes are said to improve morbidity diagnosis specificity, pre-fourth quarter 2015 rates may not be comparable with subsequent rates due to the change in coding. Results prior to and following the 2015 change from ICD-9 to ICD-10 codes should be compared cautiously given that the change in the ICD coding matrix may not be a one-to-one change (PHC4, 2018).

Pennsylvania Youth Survey (PAYS)

This survey is focused on students in sixth, eighth, 10th and 12th grades and exists to gather information about youth knowledge, attitudes, and behaviors towards alcohol, tobacco, and other drug use. Only data for 2017 was used for stratification, and all numbers reported were percentages. All calculations in the PAYS reports are based on the state sample, which is designed to gather data most representative of the state. The survey is offered to the entire state in the form of a census. While the state sample sizes were available for each year, no raw numbers were available. Without the raw numbers, no re-grouping of categories could be undertaken. Stratification of available data was obtained using the PAYS Web Tool and was limited to the questions and categories available through this tool. It was not possible to stratify responses by county for the questions of interest using this web tool. Given that no raw numbers were available, no manual calculations could be performed. Additionally, each stratification of race/ethnicity was an individual question, limiting comparison between races. (Bach Harrison, LLC, Pennsylvania State University [PSU], PAYS 2013-2017)

PRAMS

PRAMS samples mothers from Pennsylvania's annual birth certificate files in a manner that is representative of all women who delivered a live-birth infant in the state. Women in high risk populations as well as low birthweight infants are often oversampled to ensure adequate representation. Subsequently, women in the sample participate in a mixed-mode telephone and mail survey that aims to characterize maternal behaviors and access to health care and services before, during, and following pregnancy and birth. Since the PRAMS survey's inception in 1987, the core questionnaire developed by the CDC has been revised multiple times, and each new revision has been implemented in different phases (CDC, PRAMS, 2020).

In the present analysis, data resulting from the questionnaire implemented during Phase 7 (which took place from 2012 to 2015) were analyzed, and one indicator (marijuana use) from the state-specific supplement included in the Pennsylvania Phase 8 questionnaire implemented in 2017 was also included. Although multiple health indicators were characterized using PRAMS data, for certain indicators it was to the benefit of the assessment to use data directly available from Pennsylvania birth certificate files rather than PRAMS; the birth certificate dataset is more robust, as it contains data on all live births rather than just a sample. However, given PRAMS' extensive survey of maternal behaviors and experiences, it also provided data on certain indicators that were not available elsewhere. PRAMS also allowed for stratification by economic indicators (i.e., household income), which was not possible with birth certificate data.

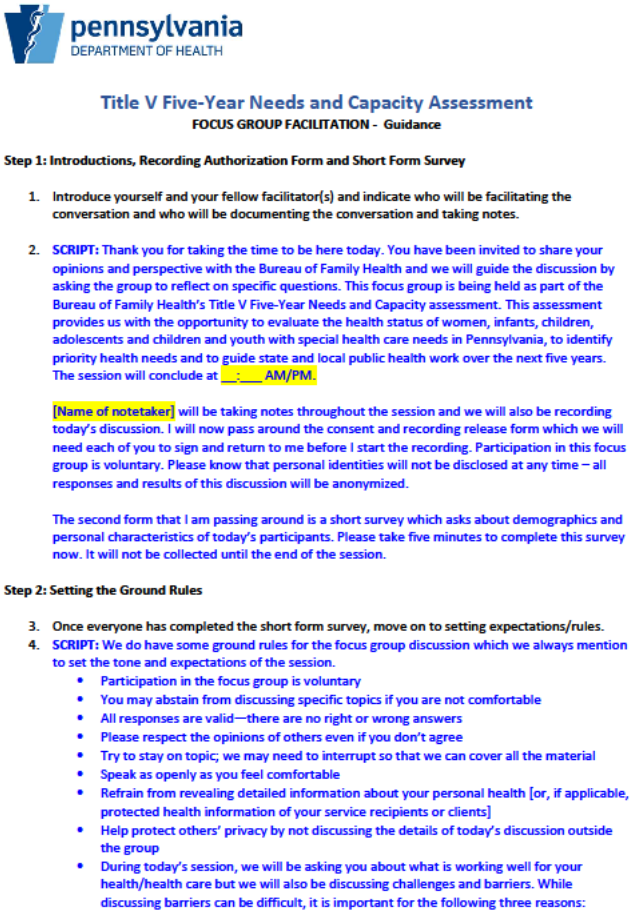
When assessing attainment of recommended weight gain during pregnancy, women that gave birth to multiple fetuses (≥ three) were not included in the assessment as there are currently no established weight guidelines for multiples beyond twins (American College of Obstetricians and Gynecologists [ACOG], 2013).

When possible, state data from Pennsylvania were compared to aggregate data from the other PRAMS sites across the nation. The 2015 PRAMS sites aggregate data presented in this report includes data from the following 34 states/sites: Alabama, Alaska, Arkansas, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, Nebraska, New Hampshire, New Jersey, New Mexico, New York City, New York State, Ohio, Oklahoma, Oregon, Pennsylvania, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming (CDC, PRAMS, 2012-2015).

Youth Risk Behavior Surveillance System (YRBSS)

Although the Youth Risk Behavior Survey (YRBS) is designed and weighted to be representative of school populations in Pennsylvania, a limitation of this dataset is the small number of surveys received each year. For example, in Pennsylvania 3,761 surveys were received in 2017, and there were approximately 580,000 high school students enrolled in Pennsylvania public schools alone during the 2016-2017 school year (CDC, YRBSS 2017). Additionally, although YRBS documentation indicates that there is broad national interest in topics including sexual education in school and food insecurity at home, such questions have not been included in the Pennsylvania YRBS and, as such, could not be characterized in the present assessment using this dataset (CDC, YRBSS, 2017).

Supplement D – Title V Five-Year Needs and Capacity Assessment Focus Group Facilitation Guide



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Title V Five-Year Needs and Capacity Assessment

FOCUS GROUP FACILITATION - Guidance

Step 1: Introductions, Recording Authorization Form and Short Form Survey

1. Introduce yourself and your fellow facilitator(s) and indicate who will be facilitating the conversation and who will be documenting the conversation and taking notes.

2. **SCRIPT:** Thank you for taking the time to be here today. You have been invited to share your opinions and perspective with the Bureau of Family Health and we will guide the discussion by asking the group to reflect on specific questions. This focus group is being held as part of the Bureau of Family Health's Title V Five-Year Needs and Capacity assessment. This assessment provides us with the opportunity to evaluate the health status of women, infants, children, adolescents and children and youth with special health care needs in Pennsylvania, to identify priority health needs and to guide state and local public health work over the next five years. The session will conclude at __:___ AM/PM.

   [Name of notetaker] will be taking notes throughout the session and we will also be recording today's discussion. I will now pass around the consent and recording release form which we will need each of you to sign and return to me before I start the recording. Participation in this focus group is voluntary. Please know that personal identities will not be disclosed at any time – all responses and results of this discussion will be anonymized.

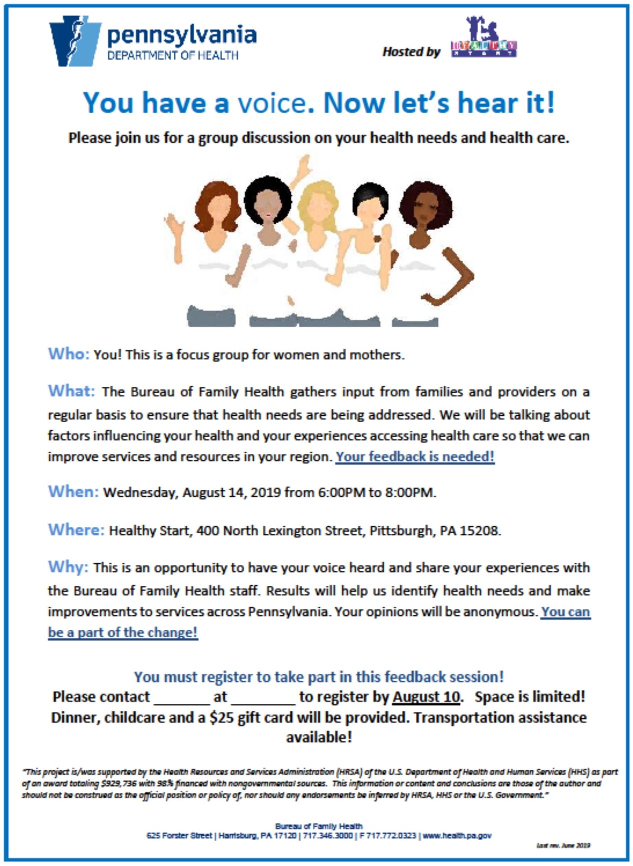
   The second form that I am passing around is a short survey which asks about demographics and personal characteristics of today's participants. Please take five minutes to complete this survey now. It will not be collected until the end of the session.

Step 2: Setting the Ground Rules

3. Once everyone has completed the short form survey, move on to setting expectations/rules.
4. **SCRIPT:** We do have some ground rules for the focus group discussion which we always mention to set the tone and expectations of the session.
   - Participation in the focus group is voluntary
   - You may abstain from discussing specific topics if you are not comfortable
   - All responses are valid—there are no right or wrong answers
   - Please respect the opinions of others even if you don't agree
   - Try to stay on topic; we may need to interrupt so that we can cover all the material
   - Speak as openly as you feel comfortable
   - Refrain from revealing detailed information about your personal health [or, if applicable, protected health information of your service recipients or clients]
   - Help protect others' privacy by not discussing the details of today's discussion outside the group
   - During today's session, we will be asking you about what is working well for your health/health care but we will also be discussing challenges and barriers. While discussing barriers can be difficult, it is important for the following three reasons:

Note: Please double click on the image to view the complete supplement.

Supplement E – Flyers Advertising Title V Five-Year Needs and Capacity Assessment



pennsylvania
DEPARTMENT OF HEALTH

Hosted by

You have a voice. Now let's hear it!

Please join us for a group discussion on your health needs and health care.

Who: You! This is a focus group for women and mothers.

What: The Bureau of Family Health gathers input from families and providers on a regular basis to ensure that health needs are being addressed. We will be talking about factors influencing your health and your experiences accessing health care so that we can improve services and resources in your region. Your feedback is needed!

When: Wednesday, August 14, 2019 from 6:00PM to 8:00PM.

Where: Healthy Start, 400 North Lexington Street, Pittsburgh, PA 15208.

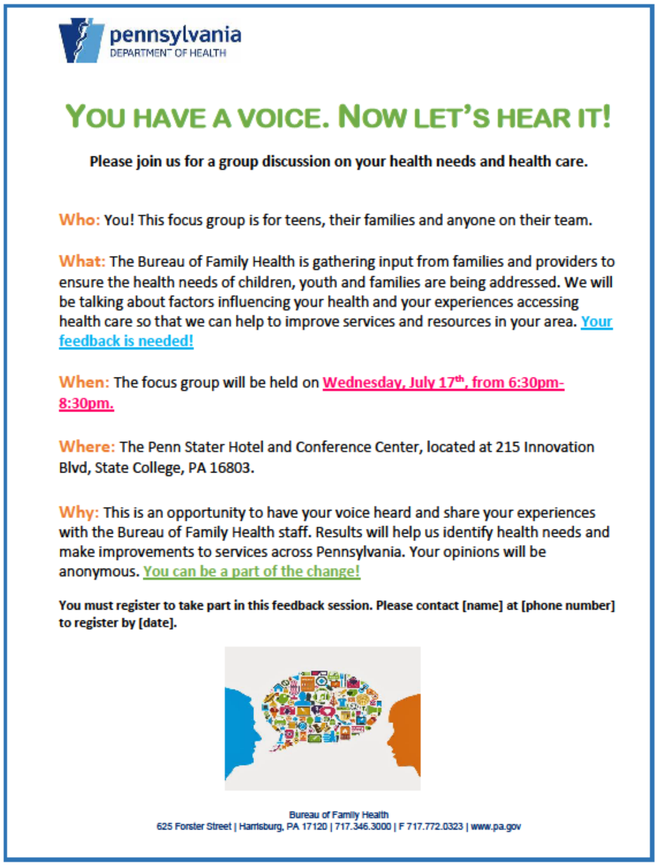
Why: This is an opportunity to have your voice heard and share your experiences with the Bureau of Family Health staff. Results will help us identify health needs and make improvements to services across Pennsylvania. Your opinions will be anonymous. You can be a part of the change!

You must register to take part in this feedback session!
Please contact _______ at ________ to register by August 10. Space is limited!
Dinner, childcare and a $25 gift card will be provided. Transportation assistance available!

"This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $929,736 with 98% financed with nongovernmental sources. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government."

Bureau of Family Health
625 Forster Street | Harrisburg, PA 17120 | 717.346.3000 | F 717.772.0323 | www.health.pa.gov

Last rev. June 2019



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YOU HAVE A VOICE. NOW LET'S HEAR IT!

Please join us for a group discussion on your health needs and health care.

Who: You! This focus group is for teens, their families and anyone on their team.

What: The Bureau of Family Health is gathering input from families and providers to ensure the health needs of children, youth and families are being addressed. We will be talking about factors influencing your health and your experiences accessing health care so that we can help to improve services and resources in your area. Your feedback is needed!

When: The focus group will be held on Wednesday, July 17th, from 6:30pm-8:30pm.

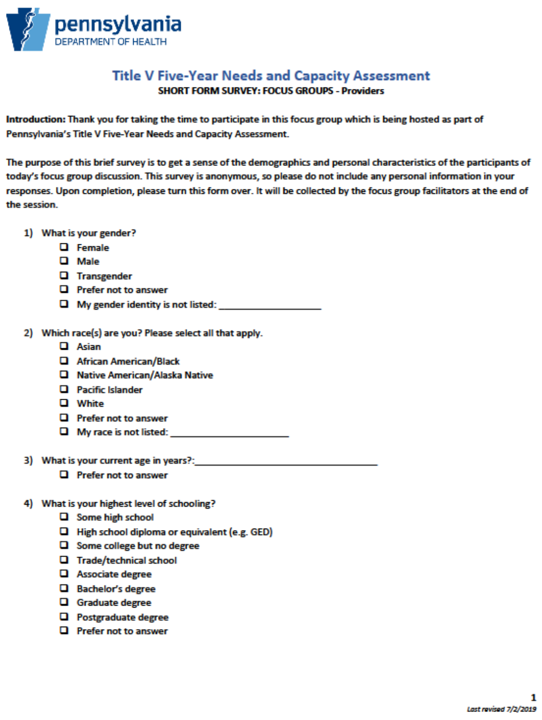
Where: The Penn Stater Hotel and Conference Center, located at 215 Innovation Blvd, State College, PA 16803.

Why: This is an opportunity to have your voice heard and share your experiences with the Bureau of Family Health staff. Results will help us identify health needs and make improvements to services across Pennsylvania. Your opinions will be anonymous. You can be a part of the change!

You must register to take part in this feedback session. Please contact [name] at [phone number] to register by [date].

Bureau of Family Health
625 Forster Street | Harrisburg, PA 17120 | 717.346.3000 | F 717.772.0323 | www.pa.gov

Supplement F – Title V Five-Year Needs and Capacity Assessment Focus Groups: Short form surveys and audio recording consent form



pennsylvania
DEPARTMENT OF HEALTH

Title V Five-Year Needs and Capacity Assessment
SHORT FORM SURVEY: FOCUS GROUPS - Providers

Introduction: Thank you for taking the time to participate in this focus group which is being hosted as part of Pennsylvania's Title V Five-Year Needs and Capacity Assessment.

The purpose of this brief survey is to get a sense of the demographics and personal characteristics of the participants of today's focus group discussion. This survey is anonymous, so please do not include any personal information in your responses. Upon completion, please turn this form over. It will be collected by the focus group facilitators at the end of the session.

1) What is your gender?
   - ☐ Female
   - ☐ Male
   - ☐ Transgender
   - ☐ Prefer not to answer
   - ☐ My gender identity is not listed: ____________________

2) Which race(s) are you? Please select all that apply.
   - ☐ Asian
   - ☐ African American/Black
   - ☐ Native American/Alaska Native
   - ☐ Pacific Islander
   - ☐ White
   - ☐ Prefer not to answer
   - ☐ My race is not listed: ____________________

3) What is your current age in years?:______________________________
   - ☐ Prefer not to answer

4) What is your highest level of schooling?
   - ☐ Some high school
   - ☐ High school diploma or equivalent (e.g. GED)
   - ☐ Some college but no degree
   - ☐ Trade/technical school
   - ☐ Associate degree
   - ☐ Bachelor's degree
   - ☐ Graduate degree
   - ☐ Postgraduate degree
   - ☐ Prefer not to answer

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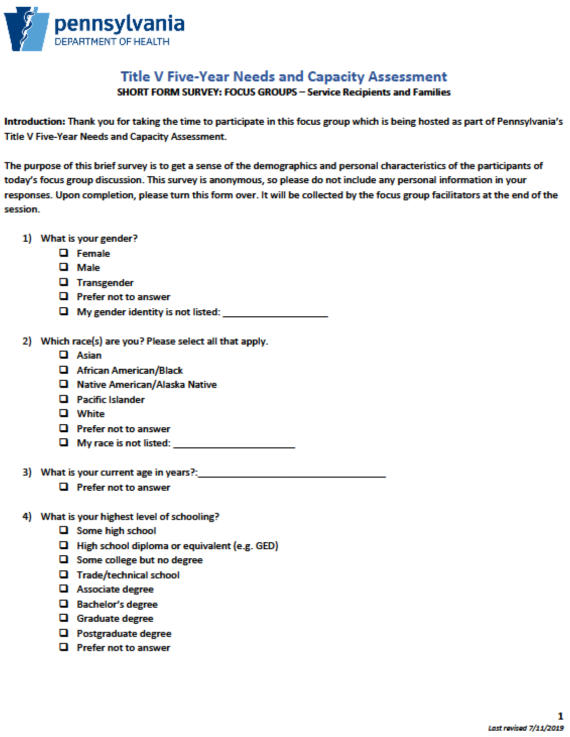
Last revised 7/2/2019



pennsylvania
DEPARTMENT OF HEALTH

Title V Five-Year Needs and Capacity Assessment
SHORT FORM SURVEY: FOCUS GROUPS – Service Recipients and Families

Introduction: Thank you for taking the time to participate in this focus group which is being hosted as part of Pennsylvania's Title V Five-Year Needs and Capacity Assessment.

The purpose of this brief survey is to get a sense of the demographics and personal characteristics of the participants of today's focus group discussion. This survey is anonymous, so please do not include any personal information in your responses. Upon completion, please turn this form over. It will be collected by the focus group facilitators at the end of the session.

1) What is your gender?
   - ☐ Female
   - ☐ Male
   - ☐ Transgender
   - ☐ Prefer not to answer
   - ☐ My gender identity is not listed: ____________________

2) Which race(s) are you? Please select all that apply.
   - ☐ Asian
   - ☐ African American/Black
   - ☐ Native American/Alaska Native
   - ☐ Pacific Islander
   - ☐ White
   - ☐ Prefer not to answer
   - ☐ My race is not listed: ____________________

3) What is your current age in years?:______________________________
   - ☐ Prefer not to answer

4) What is your highest level of schooling?
   - ☐ Some high school
   - ☐ High school diploma or equivalent (e.g. GED)
   - ☐ Some college but no degree
   - ☐ Trade/technical school
   - ☐ Associate degree
   - ☐ Bachelor's degree
   - ☐ Graduate degree
   - ☐ Postgraduate degree
   - ☐ Prefer not to answer

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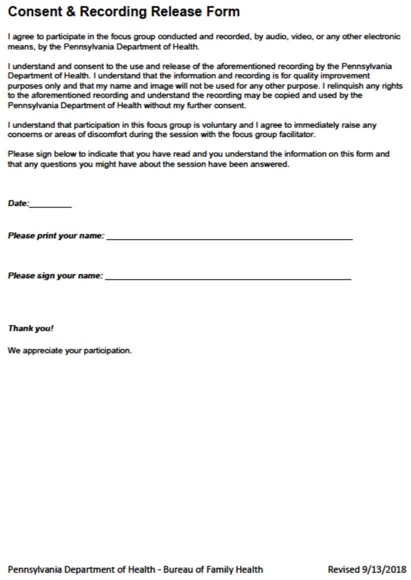
Last revised 7/11/2019



Consent & Recording Release Form

I agree to participate in the focus group conducted and recorded, by audio, video, or any other electronic means, by the Pennsylvania Department of Health.

I understand and consent to the use and release of the aforementioned recording by the Pennsylvania Department of Health. I understand that the information and recording is for quality improvement purposes only and that my name and image will not be used for any other purpose. I relinquish any rights to the aforementioned recording and understand the recording may be copied and used by the Pennsylvania Department of Health without my further consent.

I understand that participation in this focus group is voluntary and I agree to immediately raise any concerns or areas of discomfort during the session with the focus group facilitator.

Please sign below to indicate that you have read and you understand the information on this form and that any questions you might have about the session have been answered.

Date:_________

Please print your name: ____

Please sign your name: ____

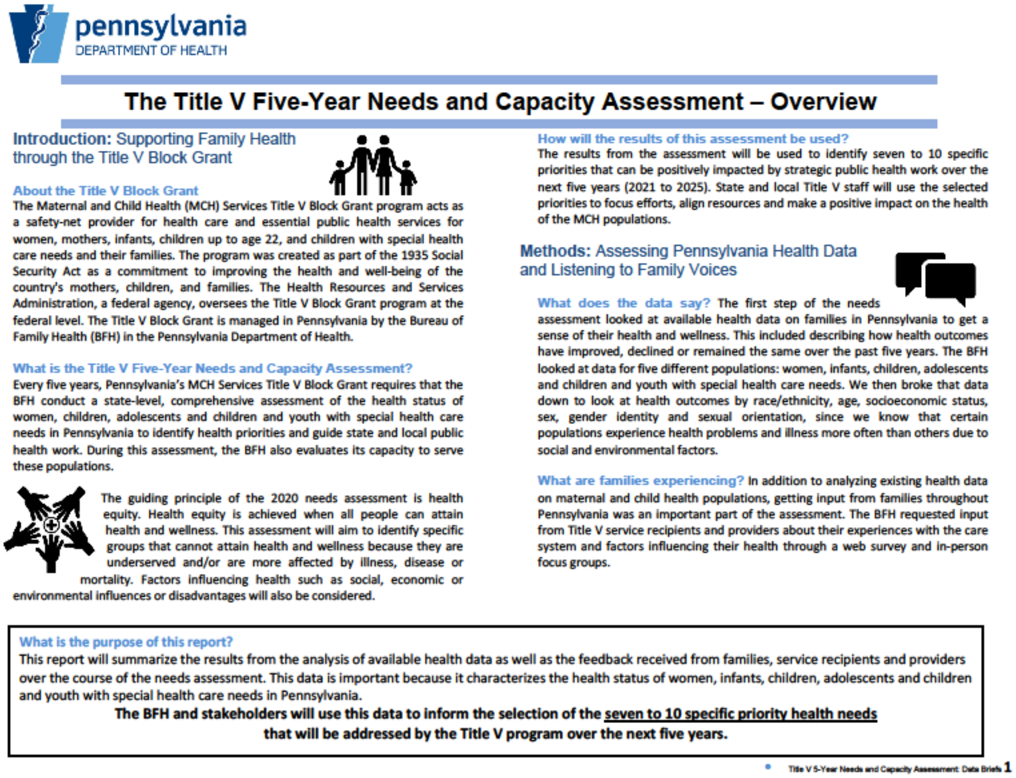
Thank you!

We appreciate your participation.

Pennsylvania Department of Health - Bureau of Family Health		Revised 9/13/2018

Note: Please double click on the image to view the complete supplement.

Supplement G – Data Briefs



pennsylvania
DEPARTMENT OF HEALTH

The Title V Five-Year Needs and Capacity Assessment – Overview

Introduction: Supporting Family Health through the Title V Block Grant

About the Title V Block Grant

The Maternal and Child Health (MCH) Services Title V Block Grant program acts as a safety-net provider for health care and essential public health services for women, mothers, infants, children up to age 22, and children with special health care needs and their families. The program was created as part of the 1935 Social Security Act as a commitment to improving the health and well-being of the country's mothers, children, and families. The Health Resources and Services Administration, a federal agency, oversees the Title V Block Grant program at the federal level. The Title V Block Grant is managed in Pennsylvania by the Bureau of Family Health (BFH) in the Pennsylvania Department of Health.

What is the Title V Five-Year Needs and Capacity Assessment?

Every five years, Pennsylvania's MCH Services Title V Block Grant requires that the BFH conduct a state-level, comprehensive assessment of the health status of women, children, adolescents and children and youth with special health care needs in Pennsylvania to identify health priorities and guide state and local public health work. During this assessment, the BFH also evaluates its capacity to serve these populations.

The guiding principle of the 2020 needs assessment is health equity. Health equity is achieved when all people can attain health and wellness. This assessment will aim to identify specific groups that cannot attain health and wellness because they are underserved and/or are more affected by illness, disease or mortality. Factors influencing health such as social, economic or environmental influences or disadvantages will also be considered.

How will the results of this assessment be used?

The results from the assessment will be used to identify seven to 10 specific priorities that can be positively impacted by strategic public health work over the next five years (2021 to 2025). State and local Title V staff will use the selected priorities to focus efforts, align resources and make a positive impact on the health of the MCH populations.

Methods: Assessing Pennsylvania Health Data and Listening to Family Voices

What does the data say? The first step of the needs assessment looked at available health data on families in Pennsylvania to get a sense of their health and wellness. This included describing how health outcomes have improved, declined or remained the same over the past five years. The BFH looked at data for five different populations: women, infants, children, adolescents and children and youth with special health care needs. We then broke that data down to look at health outcomes by race/ethnicity, age, socioeconomic status, sex, gender identity and sexual orientation, since we know that certain populations experience health problems and illness more often than others due to social and environmental factors.

What are families experiencing? In addition to analyzing existing health data on maternal and child health populations, getting input from families throughout Pennsylvania was an important part of the assessment. The BFH requested input from Title V service recipients and providers about their experiences with the care system and factors influencing their health through a web survey and in-person focus groups.

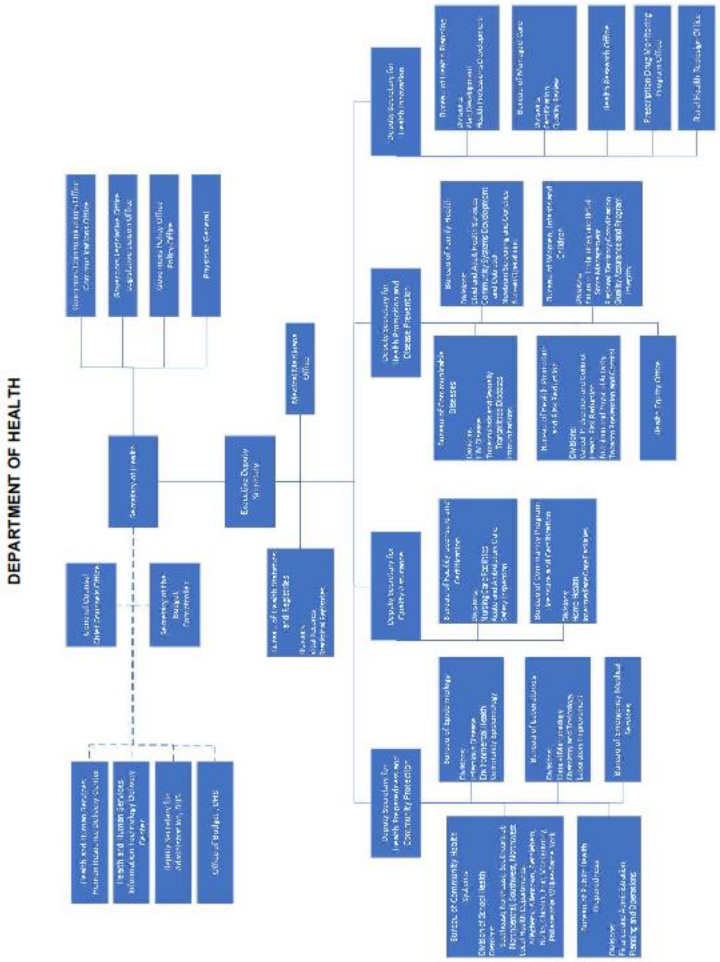
What is the purpose of this report?

This report will summarize the results from the analysis of available health data as well as the feedback received from families, service recipients and providers over the course of the needs assessment. This data is important because it characterizes the health status of women, infants, children, adolescents and children and youth with special health care needs in Pennsylvania.

The BFH and stakeholders will use this data to inform the selection of the seven to 10 specific priority health needs that will be addressed by the Title V program over the next five years.

Title V 5-Year Needs and Capacity Assessment: Data Briefs 1

Supplement H – Department of Health and Bureau of Family Health Organizational Structure



Note: Please double click on the image to view the complete supplement.

Supplement I – Table of Title V-Supported Programs and Table of Title V Program Partnerships

Supplement I Table 1: Title V-Supported Programs

Title V Program/Service	Function(s)
Sudden Infant Death Syndrome Education and Prevention Program Act, Act 73 of 2010	The BFH distributes educational materials and an acknowledgement form regarding sudden unexpected infant death (SIDS) and sudden unexplained infant death syndrome (SUID) to hospitals. This initiative is based on Act 73 of 2010.
Local Title V Programs	Ten county municipal health departments provide a variety of services aimed at improving maternal, infant and child health across the commonwealth. These health departments are in Allegheny County, Allentown, Bethlehem, Bucks County, Chester County, Erie County, Montgomery County, Philadelphia, Wilkes Barre, and York City. Programs provided through these health departments include maternal and infant home visiting, breastfeeding education and support, safe sleep and other child safety education, preconception and interconception care, screening for behavioral health, depression, substance abuse and intimate partner violence, and smoking cessation.
Centering Pregnancy Programs	This group prenatal care model is used to reduce health care disparities, promote healthy behaviors, provide peer support, improve pregnancy outcomes, and reduce infant mortality. Additionally, as part of this program, Lancaster General Hospital offers a Centering Pregnancy group for women with substance use disorder/opioid use disorder.
IMPLICIT Interconception Care (ICC)	IMPLICIT ICC is a model that identifies maternal behavioral risks during babies' well child visits, up to 2 years of age. During each well child visit, the provider assesses four components of the woman's health: smoking status, depression, birth control and folic acid intake. Women are counseled and referred for services as needed. The initiative is focused on changing maternal behaviors to improve the health of women, as well as improve birth outcomes in subsequent pregnancies. Beginning in 2020, the BFH will work with the grantee to implement a fourth trimester model of care. The project will increase the number of women receiving maternal health care within 28 days from delivery in an effort to decrease rates of maternal mortality and morbidity in the early postpartum period.

Title V Program/Service	Function(s)
Family Planning Services for Women with Opioid Use Disorder (OUD)	This project increases access to family planning care and improves detection of OUD among women and access to OUD treatment. This project builds the capacity of behavioral health professionals, through training and technical assistance, to assess women in OUD treatment programs for their pregnancy intentions and provides referrals to family planning clinics.
Reproductive Health Services	This program provides family planning services, including routine gynecological care, pregnancy testing, contraceptives, cervical cancer exam, screening and treatment for sexually transmitted diseases, education and counseling, and general health screening service to clients between the ages of 17 and 21 who are considered to be sexually active.
SafeTeens	As part of this program, the grantee maintains the SafeTeens.org website which provides Pa. adolescents with access to sexual and reproductive health care services and information. The grantee also provides the SafeTeens Answers! program which allows teens to text a question about reproductive health or healthy relationships and receive a medically accurate answer within two hours.
Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) Youth Program	This program provides services to LGBTQ youth through Persad Center's Safe Spaces Project, which include suicide prevention training to youth, and engages in coalition building activities with organizations to help them become Safe Space certified. The Mazzoni Center provides a drop-in health center for youth to obtain a variety of health care and social services.
Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) Youth Behavioral Health Services	This is a new program that will start 10/1/2020 and will provide services to LGBTQ youth to promote mental health, substance use prevention, or suicide prevention services.

Title V Program/Service	**Function(s)**
Health Resource Centers (HRC)	Reproductive health services are provided to high school students in Philadelphia, Delaware, Allegheny, Berks, Dauphin, Lackawanna, Lycoming, Fayette, Beaver, Venango, and Lehigh counties through the HRC Program. These counties were selected due to their high rates of teen pregnancy, STIs, and school dropouts. Services include counseling and education, information about reproductive health and relationships, STI screening and pregnancy testing, and referrals to school, community-based resources, and family planning network for free or low-cost reproductive health services.
Healthy Adolescents Promoted by Partnership for Youth (HAPPY)	Through this program, partnerships have been formed between schools, domestic violence prevention providers, and health care providers to conduct outreach and educational activities to prevent intimate partner violence between adolescents.
Healthy Eating Active Living (HEAL)	Through this program, the grantee provides healthy eating and active living programming to LGBTQ youth. Youth are provided with weekly healthy food demonstrations, recreational activities, and healthy living group discussions.
Bullying Prevention	This program is a modification of the Olweus Bullying Prevention Program by the developers at Clemson University. The aim of the program is to deliver the training program in community youth organizations. Eight community organizations were chosen by an RFA and began operating January 1, 2020. Staff from each organization received provisional certification in the Olweus Bullying Prevention Program in February 2020. Community youth organizations will begin programming in the late spring and summer of 2020.
Mentoring Program	Three grantees in Philadelphia county provide evidence-based mentoring to youth focused on increasing protective factors.
Safe and Healthy Homes Program (SHHP)	The SHHP is a primary prevention program targeting childhood injuries using a holistic healthy homes approach. The SHHP conducts home assessments for low-income MCH populations to identify healthy and safety hazards. Evidence-informed education and interventions are provided to remedy hazards using a healthy homes approach. The SHHP provides additional resources to local resources to address health, education, and other needs that are beyond the scope of the program.
Infant Safe Sleep Initiative	The Infant Safe Sleep Initiative is intended to decrease infant deaths due to SUID. A hospital-based model program was developed and is being implemented for newborns to increase teaching and reinforcement of safe sleep practices. The supporting social marketing plan targets high risk and minority populations.

Title V Program/Service	Function(s)
Safety in Youth Sports Act (Act 101 of 2011)	The law is intended to protect student athletes from head injuries. As coaches are often the first line of defense in recognizing a concussion in athletes, the law offers tips and guidelines for recognizing and managing these injuries. Key components include establishing standards for managing concussions, removal from activity of an athlete that is suspected of suffering from a head injury, guidelines for returning an athlete to play once medical clearance is received, and required training for coaches.
Shaken Baby Syndrome (SBS) Prevention and Awareness Program (Act 176 of 2002)	The Shaken Baby Syndrome program is being overseen by the DOH. The DOH provides educational materials, free of charge, to the hospitals and birthing centers. Hospitals and birthing centers in Pennsylvania are required to provide the educational materials to the parents or legal guardians as outlined in Act 2002-176.
Traumatic Brain Injury School Re-Entry	A statewide school re-entry program aimed at assisting schools with the re-entry issues of children and adolescents who have sustained a TBI, this program ensures that schools are educated on the issue of TBI so that children are accurately identified and receive the appropriate interventions to succeed.
Parent Education, Advocacy and Leadership (PEAL)	Through a partnership with PEAL, Pa's federally designated Family to Family Health Information grantee, services offered for CSHCN and their families include Parent Leadership Institutes, Youth Leadership Institutes, support to grandparents raising CYSHCN, and a fatherhood conference.
Community to Home (C2H) - formerly Special Kids Network	Provides information and resources for CSHCN and their families. The new Community to Home program began implementation 10/1/19 and provides home-visiting under the community health worker model in six rural regions of Pa. Services to families will begin in 2020. The Special Kids Network hotline continues to function as a toll-free helpline by providing information and resources to families and providers.
PA Medical Home Initiative (MHI)	Based on the Educating Physicians in their Communities (EPIC) model, the MHI is a statewide education and quality improvement program, using a medical home approach to primary care as the key to improving the care provided to children, youth, and young adults in Pa., including those with special health care needs. The MHI's Transition Program identifies adult PCPs with a medical home approach and transitions pediatric patients into adult primary care.

Title V Program/Service	Function(s)
Sickle Cell Community-Based Programs	Community based organizations across the state provide community-based services, education, and psychosocial services to patients. Services include outreach, case management, transition issues, community awareness, and family support. The program also works with grantees to identify and address barriers to care within the client's community and connect clients with community supports and care coordination.
Sickle Cell Health Systems Programs	Select hospitals provide services to diagnosed patients and include diagnostic testing, transitional services, assessment, care, counseling, support, education, and preventative therapeutic interventions. The program also works with grantees to identify and address barriers to care within the client's community and connect clients with community supports and care coordination.
Child Rehabilitation Program	Hospitals and one community-based organization provide comprehensive, multidisciplinary team care to clients with neuromuscular and orthopedic disorders. The program also works with grantees to identify and address barriers to care within the client's community and connect clients with community supports and care coordination.
Autism Diagnostic Clinic	Community based organization provides early diagnosis of autism spectrum disorder (ASD) and provides care coordination, support, as well as parent and family training in therapeutic care approaches. In 2018, the Easter Seals of Eastern Pa. initiated a telehealth model in collaboration with Children's Hospital of Philadelphia and the Berks County Early Intervention Unit to identify and diagnose ASD in pre-school-aged children. Easter Seals also assisted families in identifying and applying for appropriate therapeutic services for children diagnosed with ASD. Additionally, in 2019, Easter Seals began training parents in applied behavioral analysis techniques to aid families while waiting for full therapeutic services to begin.
Spina Bifida Program	Select hospitals across the state provide comprehensive, multidisciplinary team care to pediatric and adult patients with spina bifida. The program also works with grantees to identify and address barriers to care within the client's community and connect clients with community supports and care coordination.
Male Involvement Initiative (MII)	The Male Involvement Initiative program provides the Coaching Boys into Men curriculum to young male athletes using a coach-led model. The program addresses intimate partner violence by promoting violence prevention, greater gender equity, and respectful and non-violent relationships with dating partners.

Title V Program/Service	**Function(s)**
Opioid/Brain Injury Training Program	Through this program the grantee will develop and implement a curriculum on how opioid misuse and brain injury affect one another. Training locations will be identified to serve professionals working in both the brain injury and substance misuse field on a statewide level.
Acquired Brain Injury Program (ABI)	The ABI Program provides services to individuals 18 to 21 years old who have sustained an acquired brain injury. Services include short term rehabilitation, such as cognitive therapy, assistive community integration, and work skills training, as well as case management services.
Breastfeeding Awareness and Support Program	The Keystone 10 initiative is a maternity-based breastfeeding support quality improvement initiative. Implementation has begun at 84 of the of state's 90 birthing facilities. In addition, the breastfeeding program has expanded to include community-based programs. Through a grant with AccessMatters, the program is partnering with community organizations to improve county breastfeeding rates through community outreach and other services. All services are being provided in counties with a breastfeeding rate below the statewide average of 81%.
Newborn Screening and Follow-up Program	This program assures screening and follow-up for 10 mandated conditions and 27 “follow-up” conditions by ensuring that blood spot specimen collection occurs as required by law, point of care testing occurs and screening results are reported for follow up through diagnosis. Follow-up services are provided on all infants with abnormal results. Newborns are referred to the appropriate treatment center to receive proper medical evaluation, confirmatory testing, diagnosis, and treatment. The program contracts with treatment centers to provide newborn screening evaluations and medical services. The program manages a statewide pharmacy metabolic formula distribution system that supplies formula to diagnosed Pennsylvanians up to the age of 22 months.
Newborn Hearing Screening and Follow-up Program	This program assures that all newborns are screened for hearing loss within the first 30 days of birth, are diagnosed within three months, and receive prescribed treatment or intervention services within six months of birth. Newborns receive an initial hearing screening while still in the hospital. Infants who do not pass the initial screen receive follow-up re-screening at the hospital, often as an outpatient. The BFH performs follow-up and tracking of infants not passing their follow-up re-screening. Department staff determines whether appropriate assessment and evaluation is completed in a timely fashion and that infants receive the prescribed treatment and intervention. Infants identified as being at risk of delayed onset hearing loss receive continued monitoring as appropriate. The DOH also administers infant hearing screening educational outreach and training workshops for nurses, audiologists, physicians, early intervention staff, and other concerned professionals.

Title V Program/Service	Function(s)
Child Death Review (CDR) Program	Act 87 codified the CDR Program which is designed to promote the safety and well-being of children by reducing preventable childhood fatalities. This is accomplished through systemic, multi-agency reviews of the deaths of children under the age of 21. The CDR Program facilitates the death review process, provides training and technical assistance to local teams, and makes recommendations regarding prevention programs and policies. Local CDR teams review deaths of children 21 years old and younger. In 2018, DOH reconvened the State CDR Team, which will function as a support to the local teams and address any statewide issues.
Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registries	The BFH tracks Pa. data for the CDC's National SUID and SDY Case Registries. These comprehensive data from the multidisciplinary child death review team meetings capture the circumstances surrounding SUID deaths in eleven counties and SDY deaths in Philadelphia, including each case investigation. This information is used for the development of targeted SUID reduction and prevention activities.
Pregnancy and Risk Assessment Monitoring System (PRAMS)	PA PRAMS is an epidemiologic surveillance system managed within the BFH. The program collects unique state-specific, population-based data on maternal attitudes and experiences before, during, and after pregnancy. Data are collected via mail and telephone survey by a contractor. BFH PRAMS staff analyze and disseminate data guided by programming priorities and individual requests. PA PRAMS operations are funded by the Title V Block Grant. For the 2020 birth year, Title V funds allocated to PRAMS were increased to support a larger sample size for participation in a Postpartum Assessment of Women Survey.
Neonatal Abstinence Syndrome (NAS) Follow-up Program	This program assures mandatory reporting of all Pa. NAS cases that meet Council of State and Territorial Epidemiologists confirmed or probable case definition in the Division of Newborn Screening and Genetics (DNSG) Internet Case Management System (ICMS). The DNSG will ensure birth facilities are routinely connecting families with health and social services to promote optimal child development and family well-being.

Supplement I, Table 2: Title V Program Partnerships

Title V Partnerships, Collaboration and Coordination	
Other MCHB Investments	
State Systems Development Initiative (SSDI)	The BFH administers the HRSA-funded SSDI grant that complements the Title V MCH Block Grant program by improving the availability, timeliness, and quality of MCH data. The SSDI grant is used to build MCH data capacity to support Title V programs in making data-driven decisions. Data will include sources from DOH as well as stakeholders and partners. Utilization of these data is central to the BFH's capacity to report on its Title V program, implement and evaluate its programming and complete the annual Title V MCH Block Grant application/report.
Parent Education, Advocacy, and Leadership Center (PEAL)	PEAL is the Family-to-Family Health Information Center for Pa. The BFH collaborates with PEAL to create leadership opportunities for children and youth with special health care needs.
Leadership Education in Neurodevelopmental Disabilities (LEND) Fellowship Program	The BFH partners with the LEND Program at Children's Hospital of Philadelphia (CHOP). LEND is a fellowship for professionals who are completing or recently completed an advanced degree in health care fields associated with maternal and child health, family members who care for children with neurodevelopmental or related conditions, or an individual who has experienced a disability or chronic condition in their own life, and who is looking to expand their knowledge and experience with leadership. The BFH and the LEND program maintain communication about projects related to maternal and child health and look for opportunities to collaborate. Furthermore, the BFH's family delegate serves on the LEND Community Advisory Board. Through this partnership, the LEND program is able to make appropriate referrals to the BFH's programs.
Leadership Education in Adolescent Health (LEAH) Fellowship Program	The LEAH Fellowship Program at the Children's Hospital of Philadelphia (CHOP) prepares health professionals for leadership roles in public health and focuses on improving the health and well-being of adolescents and young adults. Enhancing the capacity of Title V programs to respond to current and emerging health needs of adolescents and young adults is a specific focus of the program. Department staff meet with the LEAH fellows and their leadership once a year to provide an overview of the Title V MCH Block Grant, summarize current adolescent health programming, and discuss possible collaboration.
Drexel MCH Public Health Catalyst Program	The purpose of the Catalyst program at Drexel is to provide an increased focus on fundamental MCH content and competencies. The BFH recently developed a relationship with this program and is exploring opportunities to engage students.

Other Federal Investments	
School Re-Entry Program	The BFH represents the DOH not only as a founding partner with the Pa. Department of Education, but current leading partner for the BrainSTEPS (Strategies Teaching Educators, Parents and Students) Program. BrainSTEPS works to ensure that those who provide educational support to children with brain injury have an understanding of brain injury, its resulting challenges, and the supports and interventions that will help these students achieve optimal educational success.
Traumatic Brian Injury Implementation Grant	The BFH leads initiatives aimed at increasing awareness of brain injury. These activities include training to increase awareness of traumatic brain injury (TBI) and screening for TBI within the juvenile justice and older adult population. The BFH has also implemented a NeuroResource Facilitation Program to connect individuals with brain injury to appropriate resources. Through the federal TBI grant, the BFH serves as a mentor to other states in the areas of juvenile justice and return to learn programs.
Sudden Unexpected Infant Death (SUID)/Sudden Death in the Youth (SDY) Federal Grant	Pa. was awarded a cooperative agreement with the Centers for Disease Control and Prevention in 2018 for SUID Registry and the SDY Registry. Unexplained, undetermined, and sleep-related deaths of infants fall under the SUID registry. Sudden and unexplained deaths of children and youth from birth through age 21 fall under the SDY registry. The purpose of the registries is to understand the underlying causes of death in order to develop prevention recommendations. The work of SUID registry is supplemented with Title V monies and the work of the SDY registry is funded completely with Title V monies.
The Pennsylvania Pregnancy Risk Assessment Monitoring System (PA PRAMS)	PA PRAMS is an epidemiologic surveillance system managed within the BFH. The program collects unique state-specific, population-based data on maternal attitudes and experiences before, during, and after pregnancy. Data are analyzed and shared to inform MCH program and policy development both within the DOH and by external partners and stakeholders.
Sexual Risk Avoidance Education (SRAE)	The BFH partners with Temple University Harrisburg to implement the Teen Outreach Program (TOP) at six sites across Pennsylvania. TOP is an evidence-based, positive youth development program that promotes the healthy development of youth in grades 6-12. Temple University Harrisburg serves as the TOP replication partner and is responsible for fidelity monitoring, data collection and evaluation, training, and technical assistance.

Personal Responsibility Education Program (PREP)	The BFH administers PREP, which provides evidence-based teen pregnancy prevention programs, education on healthy relationships, adolescent development, and healthy life skills. The BFH partners with Persad Center, Inc. to provide lesbian, gay, bi-sexual, transgender, and questioning (LGTBQ) cultural competency services to PREP implementation sites. Services include an assessment of organizational LGBTQ cultural competency, LGBTQ 101 and advanced trainings for staff, as well as ongoing technical assistance.
Childhood Lead Poisoning Prevention Program (CLPPP)	The BFH administers the CLPPP by partnering with six county-municipal health departments to support activities to reduce lead exposures and lead poisoning in children under the age of six. CLPPP goals consist of increasing the number of children tested, enhancing its ability to collect data, using data to determine where to target interventions, educating the public and professionals working on lead poisoning prevention, identifying children who have been exposed to lead, and linking those children to appropriate follow-up services.
Maternal and Child Environmental Health Collaborative Improvement and Innovation Network (MCEH CoIIN)	BFH staff participate in the Maternal and Child Environmental Health Collaborative Improvement and Innovation Network, which seeks to strengthen blood lead testing, surveillance, population-based interventions, and processes to identity lead exposed children and linkages to service.
Child Safety Learning Collaborative (CSLC)	Staff from the BFH are participating in the CSLC. Through the CSLC, states and jurisdictions are working with one another to increase the adoption of evidence-based policies, programs, and practices at state and local levels. The collaboration aims to reduce injuries, violence, and deaths in children and adolescents ages 1 to19 in supported topics such as bullying prevention and SUID prevention.
Lead Hazard Control Program (LHCP)	With funding from the Department of Housing and Urban Development (HUD), the BFH partners with local governments to administer the LHCP in targeted areas of Pa. The program works to create lead-safe home environments for low-income families with children under age 6. Additionally, the program aims to increase the capacity of the local government to attain HUD funding directly.
Other HRSA Programs	
Newborn Hearing Screening Program	The BFH provides universal newborn hearing screening and intervention through a HRSA grant. Children identified as deaf or hard of hearing are referred to the Tuscarora Intermediate Unit, through a grant agreement, to receive parent and deaf mentor services.
State and Local MCH Programs	

Child Death Review Teams (CDR)	The BFH is responsible for administering the CDR Program and works closely with key stakeholders including the Pa. State Coroner's Association, the Department of Human Services, the Pa. State Police, Bureau of Emergency Management Services, the Pa. District Attorney's Association, as well as medical examiners, pediatricians, and neonatologists. The goal of CDR is to reduce the incidence of preventable child deaths by combining multi-agency and multi-disciplinary reviews of these deaths to identify risk and implementation and evaluation of targeted prevention efforts.
Family Planning Councils	The BFH provides Title V funding to the four family planning councils: AccessMatters, Adagio Health, Family Health Council of Central Pa., and Maternal and Family Health Services. The four councils are the designated Title X (National Family Planning Program) grantees for the state of Pennsylvania. Funds are supplemental to Title X funds and are used to provide reproductive health services to youth 21 years of age or younger.
Philadelphia Special Needs Consortium (PSNC)	The BFH partners with the PSNC, operated through the Philadelphia Public Health Department, to provide programs and resources for CSHCN and their families.
Other programs within the state Department of Health	
Bureau of Health Promotion Risk Reduction (BHPRR)	The BHPRR within the DOH administers the Violence and Injury Prevention Program and oversees the Injury and Violence Prevention Network (IVPN). It also houses the Division of Obesity, Physical Activity, and Nutrition. The Title V grant pays for 85% of a position in the Bureau of Health Promotion and Risk Reduction. This partnership with HPRR furthers the BFH's maternal and child health work across several of our programs related to child safety and injury prevention, including representation on the TBI Advisory Board; inclusion of TBI awareness activities in HPRR programs; and collaboration between CDR and Safe Kids Pa. Through this collaboration, the BFH aims to develop a comprehensive and coordinated injury prevention effort with the IVPN. Additionally, the BFH partners with the Division of Obesity, Physical Activity, and Nutrition to provide information and assistance regarding breastfeeding across Pa.
Pennsylvania Special Supplemental Nutrition Program for Women, Infants and Children (WIC)	The BFH partners with WIC to jointly develop breastfeeding education materials and to ensure that community-based breastfeeding initiatives involve collaboration with local WIC agencies and populations. Additionally, electronic records are routinely shared between the PA PRAMS program and WIC in an effort to identify telephone numbers for sampled and surveyed mothers. This collaborative relationship serves to elevate the PA PRAMS survey response rate. Lastly, BFH partners with WIC to ensure PKU formula is provided for CSHCN through 5 years of age.

Bureau of Public Health Preparedness (BPHP)	The BFH’s family advisor collaborates with the BPHP on emergency preparedness planning for CSHCN.
Office of Health Equity (OHE)	The BFH collaborates with OHE on initiatives related to health equity and ensuring that cultural and linguistic competence standards are met across the DOH and within BFH programming. The BFH uses Title V to fund a position within OHE to support this work.
Bureau of Epidemiology	The BFH is funding an MCH epidemiologist in cooperation with the Bureau of Epidemiology to provide data and trend analyses for all MCH programming within the BFH. The MCH epidemiologist allocates a large portion of their time to PRAMS and Title V Needs and Capacity Assessment analyses. The MCH epidemiologist is supported by a senior epidemiologist from the Bureau of Epidemiology.
The Pennsylvania Dept. of Health's Bureau of Health Statistics and Research (BHSR), Division of Vital Statistics	The BFH has an ongoing collaboration with BHSR. The Division of Newborn Screening and Genetics works with BHSR to ensure that all Pennsylvania newborns with a birth certificate have newborn screenings performed. Additionally, BHSR pulls the monthly PRAMS batch files from the birth certificate records in accordance with the defined sampling frame and provides PRAMS staff with the annual final birth file, which is needed by the CDC to weight the PRAMS data. Similarly, the CDR process begins when the BHSR provides vital statistics information to the BFH on a monthly and a quarterly basis. The BFH compiles the data and securely disseminates it to the local CDR teams. Local teams use this information to initiate collaborative, multidisciplinary reviews.
Bureau of Communicable Diseases	The mission of the Bureau of Communicable Diseases is to reduce the incidence and prevalence of communicable diseases in Pa. A component part of that work is to provide vaccines for specific diseases that affect infants, children, and adolescents.
Pennsylvania National Electronic Disease Surveillance System (PA-NEDSS)	PA-NEDSS is a statewide, web-based surveillance system that receives and stores reports for all diseases reportable to the DOH. Data stored within PA-NEDSS can be used to identify high-risk areas, analyze service gaps, and inform programmatic decisions. The ongoing maintenance of PA-NEDSS is a collaborative effort between DOH's Bureau of Informatics and Information Technology (BIIT) and a number of programs within the department, including those in the BFH.
Bureau of Community Health Systems (BCHS)	The BCHS, through the six health districts, operates a network of state health centers and supports public health programs throughout the commonwealth. Health centers engage in community health assessment and quality assurance activities and provide other public health services, including community integration and outreach programs, to promote healthy behaviors.

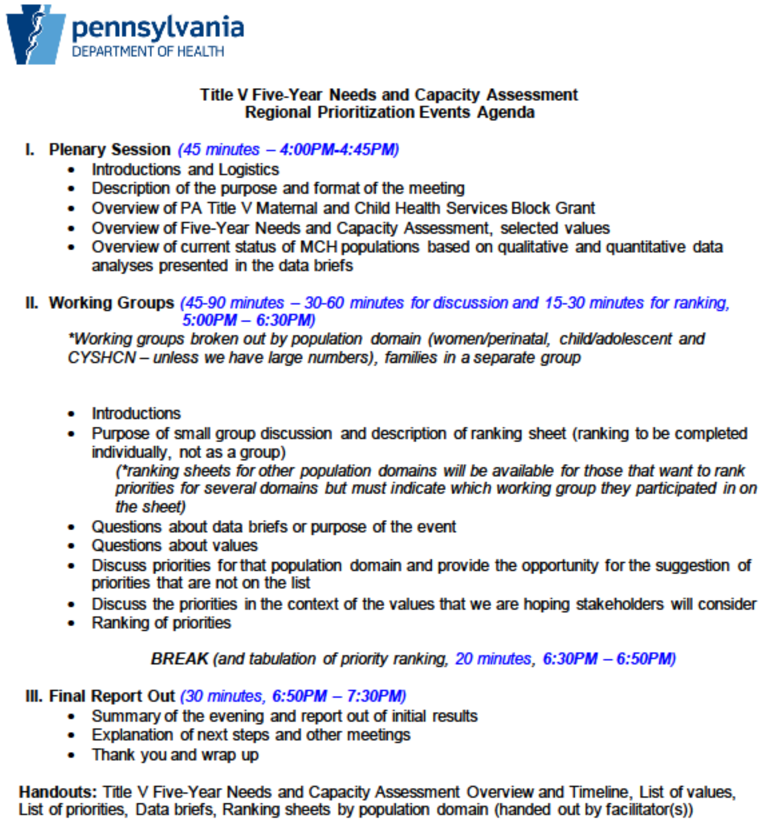
Bureau of Informatics and Technology (BIIT), Division of Health Informatics	The BFH works with BIIT to access and utilize maternal and child health data and datasets.
William Penn Fellowship Program	The William Penn Fellowship is granted to talented, passionate individuals with a commitment to public service and a drive to help make Pa. a better place to live. The program provides aspiring professionals with the opportunity to serve and learn with the state's top executive leaders. To date, the BFH has worked with a William Penn Fellow placed in the DOH on MCH policy and other related projects in Pa.
Other governmental agencies	
Lead Learning Network	The BFH participates in the Lead Learning Network, which convenes agencies across Pa. to discuss funding, programming, and strategies for reducing lead poisoning and exposure, testing all children for elevated blood lead levels, and training more lead abatement certified professionals to remove the hazard of lead from Pa.'s aging housing stock.
Department of Education (PDE)	PDE is an important partner with the BFH for CSHCN programming. They are a resource and referral source for families with concerns related to Individual Education Plans (IEPs) and 504 plans. In addition, BFH works closely with the Pennsylvania Training and Technical Assistance Network (PaTTAN) operated through the Department of Education. PaTTAN coordinates the Transition State Leadership Team, as well as the Rehabilitation for Empowerment, Natural Supports, Education, and Work (RENEW) groups on the topic of transition of CSHCN to adulthood. Additionally, BFH partners with PDE to develop school age TBI services such as the School Re-Entry Program.
Department of Labor and Industry	The BFH works with the Office of Vocational Rehabilitation (OVR) through Labor and Industry on the transition of CSHCN to adulthood.

Department of Human Services (DHS)	The BFH partners and collaborates with several different offices of DHS to meet the needs of families of CSHCN, including the Office of Medical Assistance Programs (OMAP), Office of Mental Health and Substance Abuse Services (OMHSAS), the Medical Assistance Transportation Program (MATP), and the Office of Child Development and Early Learning (OCDEL), which is an office operated jointly by the Departments of Education and Human Services. The Division of Newborn Screening and Genetics collaborates with OCDEL to share data related to Early Intervention at-risk tracking for newborns born with NAS. Additionally, callers to the Healthy Baby helpline are often referred to the online COMPASS program where individuals can apply for medical assistance and other benefits. Further, the BFH collaborates with DHS on a childhood lead data match project. On a quarterly basis, claims data for Medical Assistance (MA) children are matched against BFH data on children who were tested for lead poisoning. BFH staff also participate on the Fetal Alcohol Syndrome Disorder (FASD) Task Force to assist in the development of a comprehensive system of care for individuals born with a FASD. Additionally, MA pays for newborn screening costs associated with the filter paper blood specimen and PKU monitoring.
Pennsylvania Department of Transportation (PENNDOT)	A collaborative relationship between the DOH's Child Death Review (CDR) Program and PENNDOT serves to enhance child death review capacity. In securing traffic death information, the CDR program is able to provide local teams with critical information surrounding traffic fatalities.
Public health and health professional education programs and universities	
The Bloustein Center for Survey Research (BCSR) at Rutgers University	The BFH collaborates with the BCSR to administer PA PRAMS survey operations. The BFH is also partnering with BCSR to conduct a mixed-methods evaluation of the Pennsylvania Medical Home Initiative.
Trustees of the University of Pennsylvania	The BFH collaborates with the trustees of the University of Pennsylvania to provide interconception care to mothers between pregnancies to improve health outcomes for women, newborns, and children. The BFH collaborates with the trustees to implement a hospital-based model safe sleep program throughout Pa. as well as a social marketing plan.

Clemson University	The BFH partners with the Clemson University Institute on Family and Neighborhood Life to train and certify community youth organizations to implement the Olweus Bullying Prevention Program.
The Pennsylvania State University (PSU)	The BFH partners with PSU as a grantee implementing the Personal Responsibility Education Program (PREP) to youth. The program provides youth with information on abstinence, contraception, healthy relationships, adolescent development, and life skills.
University of Pittsburgh	The BFH supports the University of Pittsburgh as they oversee the collection of data through the Behavioral Risk Factor Surveillance System (BRFSS) for Pennsylvania.
Specialty Care Program	The BFH administers over 35 contracts with the major health systems in Pa. The Specialty Care Program provided services to Pa. residents with sickle cell disease, spina bifida, hemophilia, cystic fibrosis, Cooley's anemia, autism, and neuromuscular and orthopedic conditions. The Specialty Care Program utilizes Title V and state funds to enhance care coordination, improve access to care, enhance individualized care planning, increase mental health screenings, and engage clients and families in program services. One of the Specialty Care Program grantees is Drexel University.
Family/Consumer Partnerships and Leadership Programs	
Traumatic Brain Injury Advisory Board (TBI)	The BFH supports the TBI Advisory Board, which is comprised of an ethnically and culturally diverse group of individuals who have a commitment to serving those with brain injuries. Advisory board members include individuals living with TBI, family members of individuals with TBI, representatives from a number of government agencies, and community-based organizations in TBI service provision and advocacy.
The Pennsylvania Perinatal Partnership (PPP)	The PPP represents the collaborative efforts of Pa.'s Healthy Start Projects and Maternal and Child Health Programs. There is an ongoing collaboration between PA PRAMS, administered by the BFH, and the PPP.

Eastern Pa. Special Needs Consortium (Association)	The BFH supports the Eastern Pa. Special Needs Consortium as a formal network for medical providers, social service providers, legal advocates, local and state health departments, and parents of technology-assisted children to learn more about issues related to care of technology-assisted children.
PRAMS Committee	As part of participation in PRAMS, the BFH is required to have a PRAMS steering committee. The PRAMS Committee is currently composed of 14 members including DOH staff and stakeholders representing a variety of maternal and child health programs and services.
Newborn Screening Technical Advisory Board/Newborn Hearing Screening Technical Advisory Committee	The BFH supports both the Technical Advisory Board and the Technical Advisory Committee to provide expertise, medical advice on medications, and guidance on program improvement. The board deals with issues related to the metabolic portion of the Newborn Screening Program and the committee deals with issues related to the hearing portion of the program.

Supplement J – Regional Prioritization Meetings: Agenda



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Title V Five-Year Needs and Capacity Assessment
Regional Prioritization Events Agenda

I. Plenary Session *(45 minutes – 4:00PM-4:45PM)*

- Introductions and Logistics
- Description of the purpose and format of the meeting
- Overview of PA Title V Maternal and Child Health Services Block Grant
- Overview of Five-Year Needs and Capacity Assessment, selected values
- Overview of current status of MCH populations based on qualitative and quantitative data analyses presented in the data briefs

II. Working Groups *(45-90 minutes – 30-60 minutes for discussion and 15-30 minutes for ranking, 5:00PM – 6:30PM)*

**Working groups broken out by population domain (women/perinatal, child/adolescent and CYSHCN – unless we have large numbers), families in a separate group*

- Introductions
- Purpose of small group discussion and description of ranking sheet (ranking to be completed individually, not as a group)
  *(*ranking sheets for other population domains will be available for those that want to rank priorities for several domains but must indicate which working group they participated in on the sheet)*
- Questions about data briefs or purpose of the event
- Questions about values
- Discuss priorities for that population domain and provide the opportunity for the suggestion of priorities that are not on the list
- Discuss the priorities in the context of the values that we are hoping stakeholders will consider
- Ranking of priorities

BREAK (and tabulation of priority ranking, 20 minutes, 6:30PM – 6:50PM)

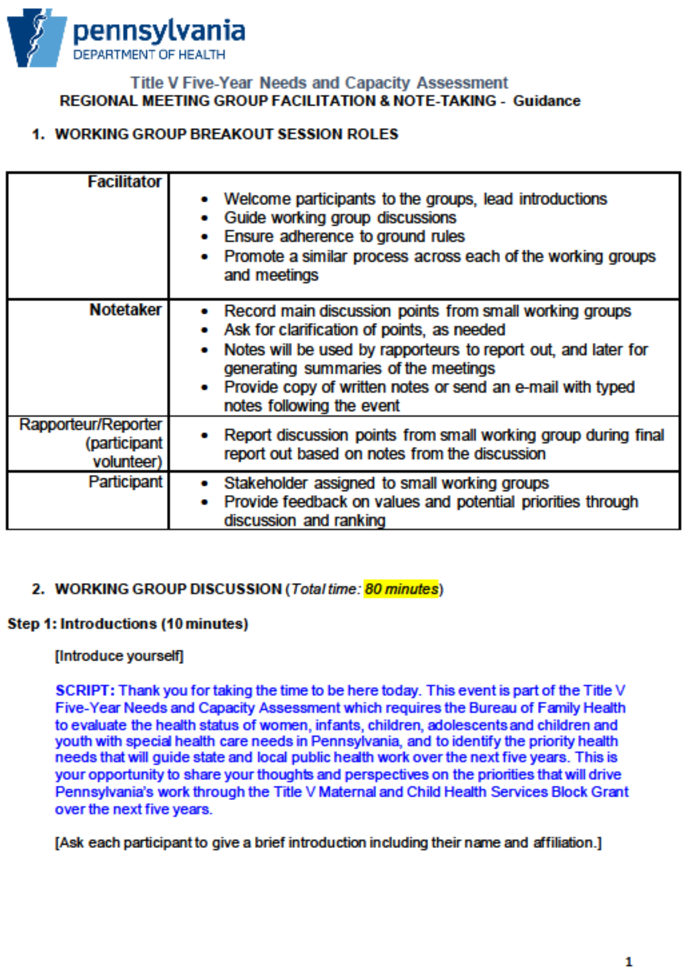
III. Final Report Out *(30 minutes, 6:50PM – 7:30PM)*

- Summary of the evening and report out of initial results
- Explanation of next steps and other meetings
- Thank you and wrap up

Handouts: Title V Five-Year Needs and Capacity Assessment Overview and Timeline, List of values, List of priorities, Data briefs, Ranking sheets by population domain (handed out by facilitator(s))

Note: Please double click on the image to view the complete supplement.

Supplement K – Regional Prioritization Meetings: Working Group Facilitation Guide



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Title V Five-Year Needs and Capacity Assessment
REGIONAL MEETING GROUP FACILITATION & NOTE-TAKING - Guidance

1. WORKING GROUP BREAKOUT SESSION ROLES

Facilitator	• Welcome participants to the groups, lead introductions • Guide working group discussions • Ensure adherence to ground rules • Promote a similar process across each of the working groups and meetings
Notetaker	• Record main discussion points from small working groups • Ask for clarification of points, as needed • Notes will be used by rapporteurs to report out, and later for generating summaries of the meetings • Provide copy of written notes or send an e-mail with typed notes following the event
Rapporteur/Reporter (participant volunteer)	• Report discussion points from small working group during final report out based on notes from the discussion
Participant	• Stakeholder assigned to small working groups • Provide feedback on values and potential priorities through discussion and ranking

2. WORKING GROUP DISCUSSION (*Total time: 80 minutes*)

Step 1: Introductions (10 minutes)

[Introduce yourself]

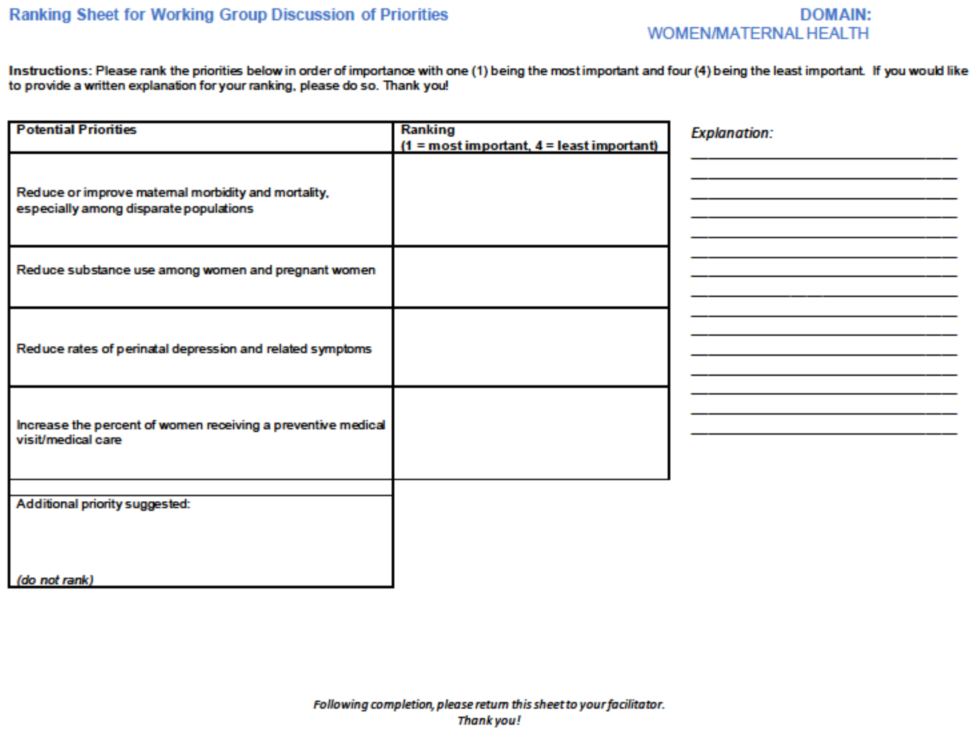
SCRIPT: Thank you for taking the time to be here today. This event is part of the Title V Five-Year Needs and Capacity Assessment which requires the Bureau of Family Health to evaluate the health status of women, infants, children, adolescents and children and youth with special health care needs in Pennsylvania, and to identify the priority health needs that will guide state and local public health work over the next five years. This is your opportunity to share your thoughts and perspectives on the priorities that will drive Pennsylvania's work through the Title V Maternal and Child Health Services Block Grant over the next five years.

[Ask each participant to give a brief introduction including their name and affiliation.]

1

Note: Please double click on the image to view the complete supplement.

Supplement L – Regional Prioritization Meetings: Example of Stakeholder Ranking Sheet, Women/Maternal Health



Ranking Sheet for Working Group Discussion of Priorities

DOMAIN:
WOMEN/MATERNAL HEALTH

Instructions: Please rank the priorities below in order of importance with one (1) being the most important and four (4) being the least important. If you would like to provide a written explanation for your ranking, please do so. Thank you!

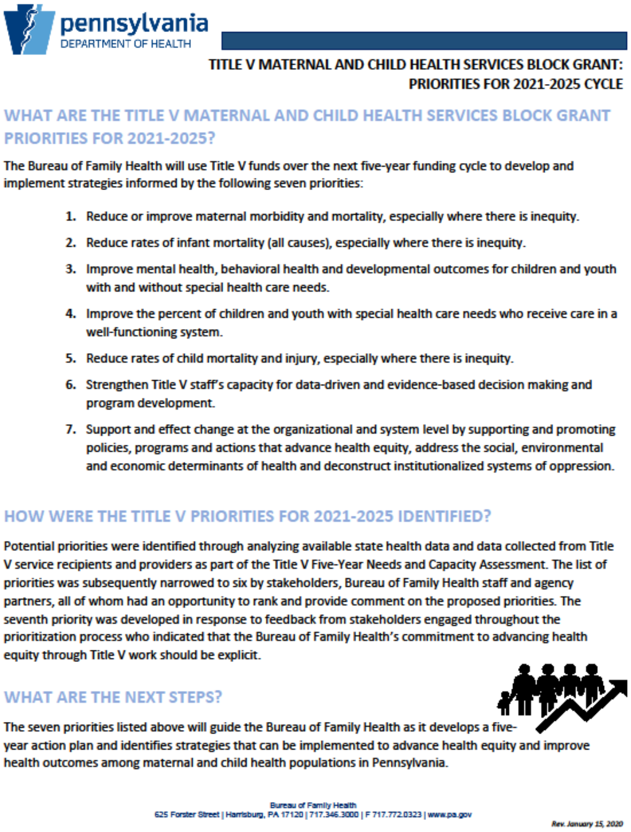
Potential Priorities	**Ranking** **(1 = most important, 4 = least important)**
Reduce or improve maternal morbidity and mortality, especially among disparate populations	
Reduce substance use among women and pregnant women	
Reduce rates of perinatal depression and related symptoms	
Increase the percent of women receiving a preventive medical visit/medical care	
Additional priority suggested: *(do not rank)*	

Explanation:

Following completion, please return this sheet to your facilitator.
Thank you!

Note: Please double click on the image to view the complete supplement.

Supplement M – Summary of Final Title V Priorities for Pennsylvania’s Maternal and Child Health Services Block Grant, 2021-2025



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TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT:
PRIORITIES FOR 2021-2025 CYCLE

WHAT ARE THE TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT PRIORITIES FOR 2021-2025?

The Bureau of Family Health will use Title V funds over the next five-year funding cycle to develop and implement strategies informed by the following seven priorities:

1. Reduce or improve maternal morbidity and mortality, especially where there is inequity.
2. Reduce rates of infant mortality (all causes), especially where there is inequity.
3. Improve mental health, behavioral health and developmental outcomes for children and youth with and without special health care needs.
4. Improve the percent of children and youth with special health care needs who receive care in a well-functioning system.
5. Reduce rates of child mortality and injury, especially where there is inequity.
6. Strengthen Title V staff’s capacity for data-driven and evidence-based decision making and program development.
7. Support and effect change at the organizational and system level by supporting and promoting policies, programs and actions that advance health equity, address the social, environmental and economic determinants of health and deconstruct institutionalized systems of oppression.

HOW WERE THE TITLE V PRIORITIES FOR 2021-2025 IDENTIFIED?

Potential priorities were identified through analyzing available state health data and data collected from Title V service recipients and providers as part of the Title V Five-Year Needs and Capacity Assessment. The list of priorities was subsequently narrowed to six by stakeholders, Bureau of Family Health staff and agency partners, all of whom had an opportunity to rank and provide comment on the proposed priorities. The seventh priority was developed in response to feedback from stakeholders engaged throughout the prioritization process who indicated that the Bureau of Family Health’s commitment to advancing health equity through Title V work should be explicit.

WHAT ARE THE NEXT STEPS?

The seven priorities listed above will guide the Bureau of Family Health as it develops a five-year action plan and identifies strategies that can be implemented to advance health equity and improve health outcomes among maternal and child health populations in Pennsylvania.

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Rev. January 15, 2020

Note: Please double click on the image to view the complete supplement.