

# NEW JERSEY MATERNAL AND CHILD HEALTH SERVICES TITLE V BLOCK GRANT

2025 Application/2023 Annual Report



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NEW JERSEY DEPARTMENT OF HEALTH

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# **III.A.** Executive Summary

# III.A.1 Program Overview

New Jersey (NJ) is one of the most ethnically and racially diverse states in the U.S. This valuable asset of population diversity demands strategic, culturally competent and thoughtful programs to address the varied and complex needs of its 9 million residents and 100,000 newborns each year. The New Jersey Department of Health (NJDOH) consistently assesses for population health needs, crafts public health responses based on those needs and evaluates progress throughout the course of program facilitation to ensure services are rooted in equitable, evidence-based, and trauma-informed frameworks; a task that is taken seriously and one which cannot be underestimated. The Division of Family Health Services (FHS) within NJDOH works to promote and protect the health of mothers, children, adolescents, and children with special healthcare needs and their families and to reduce disparities in health outcomes. The Maternal and Child Health Block Grant (MCHBG) Application and Annual Report that FHS submits annually to the Maternal Child Health Bureau (MCHB) provides an overview of innovative initiatives, state-supported programs, and other state-based responses to the needs of birthing people and their families. The needs assessment that is regularly conducted in concert with the NJDOH's strategic plan, the State's Health Improvement Plan, and Healthy NJ 2030 augments the collaborative process with other MCH partners.

To ensure access to enabling services and population-based preventive services, consistent with the findings of the Five-Year Needs Assessment, the goals, and State Priority Needs (SPNs) selected by FHS are built upon the work of prior MCH Block Grant Applications/Annual Reports and in alignment with NJDOH's and FHS' goals and objectives.

The SPNs are: SPN 1 - Increasing Equity in Healthy Births; SPN 2 - Reducing Black Maternal and Infant Mortality; SPN 3 - Improving Nutrition & Physical Activity; SPN 4 - Promoting Youth Development Programs; SPN 5 - Improving Access to Quality Care for CYSHCN; SPN 6 - Reducing Teen Pregnancy; SPN 7 - Improving & Integrating Information Systems; and SPN8 - Smoking Prevention.

NJ has selected the following 9 of 15 possible National Performance Measures (NPMs) for programmatic emphasis over the next five-year reporting period: NPM 1 - Well Woman Care; NPM 4 - Breastfeeding; NPM 5 - Safe Sleep; NPM 6 - Developmental Screening; NPM 9 - Bullying; NPM 11 - Medical Home; NPM 12 - Transitioning to Adulthood; NPM 13 - Oral Health; and NPM 14 - Household Smoking.

The Title V staff (TVS) collaborated with sister agencies, health systems, insurance companies, and community-based organizations to implement culturally responsive public health interventions to reduce disparities in health outcomes and to address the priority areas listed above; areas that have been emphasized during the current grant cycle based on the previous cycle's five-year needs assessment. However, as this five-year grant cycle ends, the NJ TVS have begun a Title V Block Grant Needs Assessment process to best understand the contemporary needs of NJ families and strategize on how best to meet those needs. The outcomes of the current needs assessment will direct the state's momentum toward focus areas that warrant acute attention. Some focus areas may remain the same while others may change, depending on the data gathered during the process.

### Maternal/Women's/Reproductive Health & Perinatal/Infant's Health

Since 2018, and in response to NJ's maternal and infant health crisis, multiple entities have come together to address the disparities that exist in maternal and infant health outcomes in the state. This work has included both an enhancement of previous, successful efforts advanced throughout the state, as well as a commitment to funding innovative programs with the goal of eliminating these disparities. One of the initiatives previously funded and since expanded is the Healthy Women, Healthy Families initiative (HWHF). Through the HWHF initiative, the NJ TVP has taken a targeted approach to reduce Black infant mortality rates beginning in 2018. As a result, partners from the Departments of Labor and Workforce Development, Education, Transportation, Children and Families, Human Services, and Community Affairs, as well as community partners, regularly collaborate with NJDOH to address the high Black infant mortality rates. One of the most salient aspects of the HWHF initiative is the implementation of specific mortality reduction activities. To better address potential adverse health outcomes post-delivery, the American College of Obstetricians and Gynecologists recently updated the postpartum guideline; instead of a routine checkup that is done 4 to 6 weeks after giving birth, the new recommendation states that the postpartum visit should be ongoing. Considering this novel change to holistically serve the MCH population, recent TVP efforts include an emphasis on the 4th trimester (i.e., postpartum period) and contemporary ways to focus on and expand breastfeeding support and postpartum doula services.

To ensure the sustainability of community doula services, NJ TVP partnered with the NJ Department of Human Services (DHS) to offer doula services to women through Medicaid Benefits. NJ Medicaid benefits have been expanded to cover doula services. Presently, NJ birthing people whom Medicaid covers can receive services from a Medicaid-enrolled community doula. The genesis of these efforts is rooted in the State's focus on health equity initiatives across populations. Additional support for birthing people, both during pregnancy and in the acute aftermath, can enhance the overall health of both mother and child resulting in healthier families and communities. Moreover, the use of the life course framework strengthens our orientation to these disparate outcomes in maternal morbidity and mortality events as it offers a perspective on protective and risk factor disparities between different populations and throughout the course of their lives. It is through this lens from which we view the myriad factors impacting populations in our state and creating prevention and intervention efforts to address these life course issues.

In 2023, NJDOH TV program continues to develop the workforce of Community Health Workers (CHWs), to better serve families where they are. The TVP Reproductive and Perinatal Health Workforce Team announced a competitive RFA to establish the NJ Community Health Worker Hub, which was awarded to Acenda, Inc., a non-profit community focused agency based in Gloucester County. This agency, licensed by the NJ Division of Mental Health and Addiction services, offers a diverse array of clinical levels of care to those in need including outpatient substance use disorder (SUD) treatment, return-to-use prevention activities and residential treatment. The goals of this healthcare collaboration include better integration of CHWs into interdisciplinary teams addressing co-morbid diagnoses of mental health and substance use issues as well as prioritizing follow-up to care. The TVP is also strengthening existing partnerships with community colleges to enhance the statewide CHW curriculum to include additional emerging public health issues (e.g., long COVID). As of 2024, we now partner with 6 county colleges in NJ, and continue outreach to add more. For ongoing training of CHWs and clinicians, TVP

partners with Rutgers to offer Project ECHO sessions on overcoming vaccine barriers. Lastly, NJ TVP will continue working with key officials to explore expanding Medicaid benefits to cover CHW services through the 1115 Waiver. In FY2022, NJ TVP, in collaboration with the Division of Mental Health and Addiction Services, launched a pilot program to facilitate reimbursement for services provided to clients covered by Medicaid.

The NJ Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program continues to provide parents with community-based education and in-home support, including evidence-based safe sleep strategies. Additionally, NJ MIECHV continues to fund the <a href="Connecting NJ">Connecting NJ</a> (CNJ) referral system to connect New Jerseyans to programs such as HWHF, MIECHV, community resources, medical care, doula programs and social support agencies. As universal home visiting programs expand throughout the state, consumer advisory boards and local service providers will continue to offer feedback to ensure fidelity to the model of care.

NJDOH's MCH Epidemiology Team conducted a formative evaluation of the HWHF initiative synthesizing the results into a set of recommendations. These recommendations informed the development of new objectives and the decision to expand evidence-based activities (e.g., lactation education and postpartum doula care) across the State. Moreover, the MCH Epidemiology Team conducted a formative evaluation of Fetal Alcohol Spectrum Disorders (FASD) Prevention and Postpartum Depression and Mood Disorders (PPD-MD) initiatives. The evaluation project informed necessary culturally sensitive programmatic changes and the development of new objectives that seek to improve health outcomes related to FASD and PPD-MD.

In FY23, TVP launched the Alma Program Expansion Project, which aims to support pregnant persons who may be experiencing mental health issues and/or substance misuse. <u>Alma</u> is an evidence-based peer specialist program developed by the University of Colorado – Boulder, and now expanded in NJ to also include substance misuse support from peers with lived experience. This expansion phase includes additional training for peers, outreach to the community and sustainability planning to provide new and expectant parents the knowledge, skills, and confidence they need to parent.

In addition to the expansion of existing programs, the NJ TVP MCH team is implementing the Preterm Birth Prevention Program as racial and ethnic disparities persist in preterm birth rates. One of the key activities is the creation of statewide clinical service best practices standards (one for 17P administration, one for cerclage, and one for vaginal progesterone cream). While piloting these resources, the team was able to expand the distribution of services to home-visiting residents, Federally Qualified Health Centers (FQHCs), patients in identified high-risk healthcare systems, and select providers. Preterm Birth Prevention activities also include clinical trainings on racism within NICU care, provided by Once Upon a Preemie.

#### Child Health

One in six children aged 3–17 has a developmental disability. Access to adequate coordinated service is paramount. Through the NJ Early Childhood Comprehensive System (ECCS) Health Integration: Prenatal to Three (ECCS P-3) Initiative, the NJ Department of Children and Families (DCF), in partnership with NJ TVP, was able to maintain integrated developmental health promotion and screening as a service of the statewide Connecting NJ system effective in FY19. Through FY20 – FY22, Connecting NJ's central hubs maintained their outreach through the pandemic and post-pandemic, which enabled thousands of children to receive parent-led developmental screenings. DCF, in partnership with TVP, plans to strengthen relationships with pediatric providers to enhance the process of referring families to the

Connecting NJ system, which links families to services and programs that support overall child and family well-being.

#### Adolescent Health

Adolescents and young adults in NJ have continued to experience disruptions to learning and other mental and physical health issues due to the COVID-19 pandemic. Adolescents continue to experience school absences and increased mental health challenges and bullying, which hit an all-time high with the return to in-person learning. Schools are still experiencing a spike in physical fights with a virtual twist as student witnesses share videos online which exacerbates the impact of the incidents. Currently, one in five students is a victim of bullying, with higher rates for adolescents with disabilities and those who identify as lesbian, gay, bisexual, transgender, non-binary, Black, Indigenous, and People of Color. This information, in addition to the Youth Risk Behavioral Surveillance data, provides additional insight into youth sexual behavior fueling the rise of sexually transmitted infections, and the needs of adolescents in NJ.

The TV MCH unit's Child and Adolescent Health Program (CAHP) plan for the upcoming year strongly focuses on bullying prevention, mental health/suicide prevention, sexual health, and school health as evidenced by the implementation of evidence-based models that help reduce bullying and stigma and improve the social-emotional atmosphere of the school. All CAH programs work together to support adolescents and their health needs holistically. Mental health and suicide prevention activities include:

- Training on screening and assessment using the Ask Suicide-Screening Questions, Columbia Suicide Severity Rating Scale, SafeSide<sup>TM</sup> Training for primary care settings, Safety Planning, Adolescent Care and Treatment of Suicide Training, and interventions for suicidal teens (Collaborative Assessment Management of Suicide and Attachment-Based Family Therapy).
- The Garrett Lee Smith Suicide Prevention Project (GLS) and MCHBG support a new learning and resource portal for professionals, parents, caregivers, and a youth named Prevent Suicide NJ (PSNJ) <a href="https://preventsuicidenj.org/">https://preventsuicidenj.org/</a>. PSNJ launched in September of 2022 and to date has provided trainings to 4,383 primary care practitioners, supported screening initiatives for 6,586 youth for suicidal ideation, provided 1,290 referrals and confirmed 684 accessed appropriate treatment. Additionally, GLS began implementation of Lifelines at five new school districts throughout NJ to further train school professionals, community partners and students in the 24-month curriculum. In addition to Lifelines Trilogy, these programs include the Teen Outreach Program (TOP®), Love Notes, and Teen Prevention Education Program.
- The Whole School, Whole Community, Whole Child School Health NJ Project, the NJ Personal Responsibility Education Program (PREP), and the NJ Sexual Risk Avoidance Education (SRAE) Program. All CAH programs support evidence-based models rooted in social and emotional learning and Positive Youth Development (PYD), proven frameworks to reduce bullying by increasing empathy and self-awareness.

Children and Youth with Special Health Care Needs (CYSHCN)

In NJ, families of CYSHCN have access to many services to ensure access to necessary services. Within the Department of Health: Family Health Services, children with special health care needs receive services through the following programs:

- Newborn Screening and Genetics Services provides timely and appropriate follow-up services for all newborns affected by an out-of-range blood spot screening result. New Jersey currently screens for 61 disorders. NJ remains among the leading states offering the most blood spot screenings. NJ's newborns are also screened with pulse oximetry through the Critical Congenital Heart Defects (CCHD) screening program. Additionally, this program oversees 12 grants to 43 specialty care programs for approximately 2.6 million dollars.
- Birth Defects Registry ensures that all children 0 through five years old who have a congenital disability are registered. Nurses work with the birthing hospitals to verify the diagnoses. Once registered, all children are referred to our Family Centered Care Services for case management services at the county level.
- Autism Registry ensures that all children 0 through 21 years old who have an autism spectrum disorder (ASD) are registered and referred to Family Centered Care Services for case management. Approximately, 53,000 children have been registered since 2009.
- The NJ EHDI Program abides by the national public health initiative "1-3-6 Guidelines." These guidelines seek to ensure that all babies born in New Jersey receive a newborn hearing screening before one month of age, complete diagnostic audiologic evaluation prior to three months of age for infants who do not pass their hearing screening and enroll in early intervention by no later than six months of age for children diagnosed with hearing loss. The EHDI program offers technical support to hospitals on their newborn hearing screening and follow-up programs.
- Family-Centered Care Services (FCCS) addresses families' medical and social conditions by
  providing resources, referrals, and support to families in obtaining accessible services within state
  departments, divisions, and county and municipal agencies. Our FCCS case managers refer
  children to NJ Early Intervention Services (NJEIS), assist with School IEP requests, transition to
  adult services and with locating services within their communities. In 2023, over 16,000 families
  received case management services.
- Specialized Pediatric Services Program (SPSP) consist of eight Child Evaluation Centers (CECs), three Pediatric Tertiary Centers, and five Cleft Lip/Palate Craniofacial Anomalies Centers. The SPS program aims to provide access to comprehensive, coordinated, culturally competent pediatric specialty and sub-specialty services to families with CYSHCN that are 21 years old or younger. In SFY22, there were a total of 117,551 patients served across all centers within the Specialized Pediatric Services Program.
- The NJ Early Intervention Services provides services to children from birth to three years of age who are experiencing developmental delays. Approximately 18,000 children receive services at any given time, including Occupational Therapy, Speech Therapy, Physical Therapy, and Developmental Intervention.
- NJ's Title V CYSHCN program collaborates with intergovernmental and community-based
  partners to ensure that care through these multiple systems is coordinated, family-centered,
  community-based, and culturally competent. Communication across state agencies and timely
  training for state employed staff, community-based organizations, and families with CYSHCN
  remain a priority to ensure that families are adequately supported.

### Cross-Cutting/Systems Building

The Oral Health Services Unit (OHSU) continues to educate the public about the importance of preventive oral health services and good oral health, with programs predominately targeted to school-aged children and pregnant women. Other preventative services include dental screening, nutrition counseling,

and placement of sealants and fluoride varnish for underserved, uninsured, and underinsured children across New Jersey. During 2021 – 2022, OHSU completed the first NJ third-grade oral health Basic Screening Survey (BSS), a national standard for establishing key oral health baseline data.

In January of 2023, NJ FamilyCare (NJ's Medicaid program) began covering dental insurance for all youth under 19 years old, and irrespective of their documentation status. This comprehensive dental program continues to extend beyond the identified population and to other eligible youth with comprehensive dental and medical benefits. To continue this important work, the Oral Health Services Unit has also expanded its dental sealant program, an evidence-based practice for low-income children and children at-risk of increased tooth decay. These and other programs have been created and expanded in response to BSS results, which found that approximately 36% of third graders in NJ experience tooth decay and disease, while the national average for the same population is around 20%. The need for continued oral health training for professionals working directly with the pregnant population is an imperative part of this work and aligns with our state goal of helping women, children and birthing people achieve full health.

#### COVID-19

The impact of COVID-19 on all areas of maternal, child, and adolescent health has caused significant shifts in our understanding of health and disease burden. Moreover, the COVID-19 emergency exacerbated the disparity chasm between populations on the margin including people of color and the impoverished and those with more privilege and resources. While the COVID-19 pandemic and public health emergency has concluded, the consequences of this chapter in our history will be experienced for generations to come. NJ TVS continue to support the work and mission of Title V program and actively works on developing innovative ways to improve the health and well-being of NJ women, children, and families. For instance, TVP partnered with Rutgers Project ECHO to develop a CHW COVID-19-specific curriculum to raise awareness, identify the impact of COVID-19 in high-risk populations and combat the ill effects of COVID-19 in NJ.

### III.A.2 How Federal Title V Funds Complement State-Supported MCH Efforts

Title V Funds are essential in supporting NJ's MCH efforts. FHS uses Title V MCH funding as a source for multiple public health interventions to address health disparities and inequities for NJ's birthing people. The current initiatives positively impact health outcomes, risk factors, chronic diseases, mental health, and the COVID-19 response. Here are a few examples of key programs funded by Title V funding:

Healthy Women, Healthy Families initiative – to fund grantees that provide services and support birthing individuals in the communities and potentially improve maternal and infant health and reduce both Black Infant and Black Maternal mortality.

<u>ConnectingNJ</u> – to fund grantees to operate and maintain a single point of entry for families to access needed resources such as home visiting, community health worker support, doula care, etc.

NJ Fetal Infant Mortality Review (FIMR) - to fund grantees to conduct FIMR-related activities (e.g., Chart review, family interview); these activities that seek to identify ways to strengthen the systems of care and resources available to families to prevent future deaths.

School Health NJ - to fund grantees working with underserved school districts in NJ to create school nurse led school health teams and implement evidence based social-emotional learning programming aligned with the CDC Whole School, Whole Community, Whole Child framework.

Title V funding serves as the main funding source used by the NJ TVP to support MCH populations in accordance with Title V and other federal and state guidelines to protect and promote the health and wellbeing of women, children, and families. Please see the Table in the Expenditures Section. It depicts the federal / state partnership and how State MCH funds support Federal Title V funds.

Title V funds are used to support NJ's state-priority MCH efforts, including increasing equity in healthy births, reducing Black infant mortality, improving nutrition and physical activity, promoting youth development, improving access to quality care for children and youth with special health care needs, reducing teen pregnancy, improving, and integrating health information systems and smoking prevention. Therefore, Title V funds are necessary to equitably improve the health of birthing people and their families in NJ.

#### III.A.3 MCH Success Stories

A. Early in 2023, a baby was born with a time critical disorder called Glutaric Acidemia type 1 (GA1). A "Time Critical" disorder is a condition in which acute symptoms or potentially irreversible damage could develop in the first week of life, and for which early recognition and treatment can reduce risk of morbidity and mortality. The presumptive positive results for this baby were 10 times the critical cutoff and were reported to the newborn screening and genetic services. Follow up team when the baby was only five days old. A call was placed to the doctor listed on the baby's blood spot card; however, the doctor was not a pediatrician, but an internist the family used for adult care. A call was then placed to the birth hospital to see if they had a different pediatric doctor listed somewhere else in the chart but, no other physician was listed. To complicate matters further, the family didn't speak English, they spoke Gujarati, an Indian dialect, which resulted in difficulty contacting referrals in an efficient matter. However, an NSGS representative was connected to the family, and one who speaks Hindi, who could then help the family navigate the healthcare systems and ultimately determined that the family needed a specialist pediatric referral.

Once the specialist was contacted, the report was reviewed, and the baby was referred to be seen immediately. The NSGS program contacted the family's internist and he agreed to reach out to the family in Gujarati, communicate the urgency of the results, and provide directions to the specialist's office. The family was able to make it to the specialist's office in less than an hour from being contacted by the internist. The baby was subsequently seen by a needed specialist within 3 hours of a critical result being reported to NSGS follow-up. The baby is now connected to consistent treatment and thriving.

B. The Healthy Women, Healthy Families program provides support for qualifying pregnant and postpartum women throughout the state, with a particular focus on connecting women with postpartum doulas and community health workers (CHWs) in the "fourth trimester". One of these CHWs was working with a client who was living at a domestic violence shelter with two children under the age of 5 with special needs. At the beginning of the case management, the client was very resistant in providing information to the CHW, but as time passed, and with the CHW's genuine care, reliability, respect, active listening, and collaborative approach, they built trust together. The client notified the CHW that she was pregnant with her third child, had no support from the biological father of the unborn baby, and was still at the domestic violence shelter. The client was worried about reaching the 3-year time limit at the shelter; the CHW worked on a plan with the client to notify the social worker about her current situation to see if

they could provide any extension or assist the client with the transition to another shelter. The plan worked, the client received an extension at the domestic violence shelter, and the social worker assisted the client with the transition to Temporary Rental Assistance Housing. The client was placed in a temporary hotel, with limited access to grocery stores and laundromats and no transportation. The CHW sourced a double stroller, clothes, diapers, and wipes to support the client during this rough time. The community also assisted the client in finding transportation for medical appointments for the children and for the client for prenatal care appointments. The Temporary Rental Assistance Housing application was approved, and the CHW worked with the client to find an apartment. Once set up, the CHW helped the client find nearby pediatric clinics. The client gave birth to a healthy baby boy and learned to advocate for her family and herself. The client became an empowered woman and mother who never gave up on ensuring her children's well-being, which is a testament to her strength and determination, as well as the invaluable support provided by the CHW. Note from this CHW: "I am beyond blessed to have been part of my client's journey; I provided holistic care and assistance and advocated for my client's needs and rights. Overall, this story is a powerful reminder of the positive impact that dedicated individuals and supportive communities can have in helping families overcome adversity and build brighter futures. It highlights the importance of empathy, advocacy, and collaboration in promoting urban health, well-being, and resilience."

C. The Family Centered Care Services Case Manager (FCCS CM) received a new referral from the Autism Registry for a child who was registered at 11 years old, but who had been diagnosed at age three. The child has autism and moderate intellectual disability. After a short time working with the mother, the case manager came to realize that mom also has an intellectual disability. The dad has a job that keeps him away from the house for long periods of time, which leaves the mother to handle most of the child's care. Working with the case has been challenging because recommendations must be repeated many times for the parent to understand, and even then, the mother frequently calls our program to review/repeat what she understood and how to move forward in receiving care.

To complicate the situation further, the child was in the public school and having difficulty. The child had an IEP, but the parent was unable to read the document and did not receive the appropriate support from the school. The case manager had to reorient the mother to understand the process of how to request a change of placement, which resulted in the child being placed at private school. Due to this case's intensity of need, our FCCS CMs remained consistent in the life of the family, helping to connect the child to practitioners and services that were accessible while supporting the parents in their decision-making. After seven years of accompaniment by our case managers, this child has graduated into the 18–21-year-old program where she is doing well.

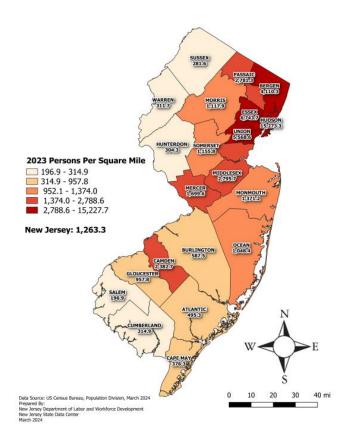
#### III.B. Overview of the State

The Maternal and Child Health Block Grant Application and Annual Report, submitted annually to the MCHB, provides an overview of initiatives, State-supported programs, and other State-based responses designed to address the MCH needs in NJ. FHS in the NJDOH Public Health Services Branch posts a draft of the MCHBG Application and Annual Report to its website in the second quarter of each calendar year to receive feedback from the maternal and child health community. Concomitantly, feedback from family members and service recipients is provoked and subsequently incorporated in keeping with our commitment to elevate the voices of family members in the state and integrate their feedback to enhance our operations.

The mission of the Division of FHS is to improve the health, safety, and well-being of families and communities in NJ. The Division promotes and protects the health of mothers, children, adolescents, and at-risk populations and reduces disparities in health outcomes by ensuring access to quality comprehensive care. The Division's ultimate goals are to enhance the quality of life for each person, family, and community and to invest in future generations' health.

In 2023, NJ's population density (persons per square mile) was 1,263 to 1 compared with 93 to 7 nationally. There are 564 municipalities and 21 counties in NJ. In 2022, based on statistics released by the Census Bureau the most populated counties in NJ are in the northern part of the state; these are Bergen, and Essex counties, with a population of 953,540 and 851,117, respectively. While Bergen is one of the most populated counties, it is also one of the top 5 most densely populated (Figure 1).





According to the 2023 population estimates of race, 52.9% of the population were White non-Hispanic; 15.4% Black; 10.5% Asian; 0.1% American Indian and Alaska Native; and 2.4% reported two or more races. In terms of ethnicity, 21.9% of the population was Hispanic. The 2022 American Community Survey identified that 32.3% of NJ residents speak a language other than English at home, compared to 22.0% nationally.

The racial and ethnic mix for NJ mothers, infants, and children is more diverse than the overall population composition. According to 2022 birth certificate preliminary data, 28.8% of mothers delivering infants in

NJ were Hispanic, 45.58% White, non-Hispanic, 12.06% Black, non-Hispanic, and 10.21% were Asian, non-Hispanic. The growing diversity of NJ's maternal and child population raises the importance of addressing disparities in health outcomes and improving services to individuals with diverse backgrounds.

MCH priorities continue to be a focus for the NJDOH. FHS, the Title V agency in NJ, has identified 3 priority goals for the MCH population: 1) improving access to health services thru partnerships and collaboration, 2) reducing disparities in health outcomes across the lifespan, and 3) increasing cultural appropriate services. These goals are consistent with the Life Course Framework, which proposes that an interrelated web of social, economic, environmental, and physiological factors contribute to good health and well-being through the course of a person's life and across generations. Moreover, the timing and severity of both protective and risk factors propel individuals and communities toward certain health statuses. This framework undergirds the work of the State's TVP as it endorses a person-in-environment perspective, positing that the interplay of micro, mezzo and macro level forces influence individuals, families, and communities. In applying the Life Course Framework in the TVP efforts of the State, programs are created to capitalize on protective factors inherent in families and communities, and to reduce risk factors that negatively impact the State's diverse populations. The TVP in NJ understands that the health of a baby depends on both past, present, and future opportunities for full actualization.

Social determinants of health, the conditions in which people live, learn, work, play, worship, and age significantly affect health, functioning, and quality of life. <u>Healthy People 2030</u> identifies five key areas: economic stability, education, social and community context, health and health care, and neighborhood and built environment. Moreover, there is a heightened need for integrating state agencies with external partners, in addressing infant and maternal mortality, the opioid crisis and other public health issues in NJ.

The selection of NJ's eight State Priority Needs is a product of FHS's continuous needs assessment. Influenced by the MCH Block Grant needs assessment process, the NJDOH budget process, the NJ State Health Improvement Plan, Healthy NJ 2030, Community Health Improvement Plans, and the collaborative process with other MCH partners. FHS has selected the following State Priority Needs:

- SPN # 1- Increasing Equity in Health Births,
- SPN # 2- Reducing Black Maternal and Infant Mortality,
- SPN #3- Improving Nutrition & Physical Activity,
- SPN # 4- Promoting Youth Development Programs,
- SPN # 5- Improving Access to Quality Care for CYSHCN,
- SPN # 6- Reducing Teen Pregnancy,
- SPN #7- Improving & Integrating Information Systems, and
- SPN #8- Smoking Prevention.

These goals and SPNs are consistent with the findings of the Five-Year Needs Assessment and are built upon the work of prior MCH Block Grant Applications/Annual reports. Consistent with federal guidelines from the MCHB, Title V services within FHS will continue to support enabling services, population-based preventive services, and infrastructure services to meet the health of all NJ families. During a period of economic hardship and federal funding uncertainty, health emergency challenges persist in

promoting access to services, reducing racial and ethnic disparities, and improving cultural competency of healthcare providers and culturally appropriate services.

Based on NJ's eight selected SPNs as identified in the Five-Year Needs Assessment, NJ has selected the following 8 of 15 possible NPMs for programmatic emphasis over the next five-year reporting period:

NPM # 1- Well Woman Care,

NPM # 4- Breastfeeding,

NPM # 5- Safe Sleep,

NPM # 6- Developmental Screening,

NPM # 9- Bullying,

NPM # 11- Medical Home,

NPM # 12- Transitioning to Adulthood,

NPM # 13- Oral Health, and

NPM #14- Household Smoking.

State Performance Measures have been reassessed through the needs assessment process. The existing SPMs which will be continued are:

SPM #1- Black Non-Hispanic Preterm Infants in NJ,

SPM # 2- The percentage of children (≤6 years of age) with elevated blood lead levels (≥10 ug/dL)

SPM #3- Percentage of NJ resident newborns discharged from NJ hospitals who did not pass their newborn hearing screening and have a documented outpatient audiological follow-up visit

SPM # 4- Referral from BDARS to Case Management Unit,

SPM # 5- Age of Initial Autism Diagnosis,

SPM # 6- Teen Outreach Program (TOP®), Reducing the Risk, Teen Prevention Education Program (PEP) and Lifelines completion, and

SPM # 7- Black, Non-Hispanic Infant Mortality in NJ.

The Title V MCH Block Grant Five-Year Needs Assessment Framework Logic Model summarizes the selected eight NPMs and aligns the impact of Evidence-Based Informed Strategy Measures (ESMs) on NPMs and NOMs. The ESMs aim to identify NJ TVP efforts that can contribute to improved performance, relative to the selected NPMs. The Logic Model is organized with one NPM per row. The Logic Model is the key representation that summarizes the Five-Year Needs Assessment process and includes the three-tiered performance measurement system with ESMs, NPMs, and NOMs. The Logic Model represents a more integrated system created by the three-tiered performance measure framework, which ties the ESMs to the NPMs, in turn, influencing the NOMs. Considering the high rate of adverse birth and pregnancy outcomes in NJ, the NJ TVP staff have been collaborating with community-based

organizations to strategically address these adverse birth outcomes which continue to disproportionately impact birthing people and families of color and frequently impoverished.

As this final year of the five-year grant cycle comes to a close, the NJ TVS has begun an 18-month needs assessment process to answer three primary questions: 1) How have the most recent five-year grant cycle state priority needs been met vis a vis our Title V initiatives?, 2) What gaps in services occurred, if any, and why?, 3) How are the current needs of NJ residents different from the past grant cycle, and how can we best strategize to address these concerns? Using the Title V Block Grant performance measurement framework as a guide, and in tandem with feedback from professionals in the field, grantees and service recipients, the needs assessment will offer insight into what services are needed for families in NJ to become fully actualized.

### Maternal / Women / Reproductive Health & Perinatal / Infant Health

The Healthy Women, Healthy Families Initiative was relaunched this fiscal year with grants awarded on July 1, 2023. This initiative continues to focus on improving maternal and infant health outcomes for women of childbearing age (defined by CDC as 15-44 years of age) and their families, especially Black families, through a collaborative and coordinated community-driven approach. First, we continue to fund the SIDS Center of NJ at Rutgers Robert Wood Johnson Medical School, to provide education and research to reduce sudden unexpected death of infants. In addition, the Healthy Women, Healthy Families program is focusing on the postpartum period through adjoining efforts of community health workers, postpartum doulas and our statewide ConnectingNJ referral hubs.

County-level community health worker case management services focus on providing high-risk families and/or women of childbearing age access to resource information and referrals to local community services that promote child and family wellness. Up until now in state FY24, over 1,700 families have been served by the CHWS who are implementing new municipality-level activities aimed at increasing postpartum care for Black and Hispanic women. These two new programs include postpartum doula services and providing breastfeeding educations sessions and support to non-traditional groups including fathers, teens, and other support persons. Connecting NJ hubs continue to partner with our maternal child health initiatives. These hubs are single points of entry for screening and referral of women of reproductive age and their families to home visiting programs and necessary medical and social services. Our HWHF community health workers continue to closely partner with our CNJ hubs to ensure a continuum of care for our maternal child health population. NJ TVP has established a CNJ committee and convenes representatives from CNJ, DCF, and NJ TVP to eliminate duplication of effort and services, ensure alignment with emerging needs, and improve the overall flow of the standardized screening tools. These tools are used for referrals to programs and services through a centralized web-based system (CNJ Link), where all clients' contacts are documented from referral to enrollment.

The purpose is to: (a) to ensure critical information is collected from all enrolled participants to guide service referrals, education, and case management planning; and (b) to collect data necessary to demonstrate the impact of the program on the well-being of women and families and birth outcomes. The top 5 Service Referrals Categories provided by CNJ from July 2018 to March 2024 included: Family

Support (28%), Nutrition (26%), Healthcare (11%), and Concrete Services (11%). For the period, the percentage of clients who mainly benefited from services offered through CNJ were 46%, 24%, 21%, 5%, and 2% for Hispanic, White Non-Hispanic (NH), Black-NH, other, and Asian, respectively.

Also, part of the ConnectingNJ referral network are connections to home visiting throughout NJ. NJ has a robust home visiting program, with NJDOH TVP collaborating with Department of Children and Families to implement the statewide network. The work of the Maternal Infant and Early Childhood Home Visiting (MIECHV) Program, aims to expand NJ's existing home visiting service system, which provides evidence-based family support services to improve family functioning, prevent child abuse and neglect; and promote child health, safety, development, and school readiness. Home visiting promotes a system of care for early childhood and is based in the life course framework as well.

The creation of the NJ Doula Learning Collaborative aligns with the First Lady Tammy Murphy's Nurture NJ initiative to improve birth outcomes and achieve equity in maternal and infant health. The Doula Learning Collaborative (DLC) aims to reduce maternal and infant mortality and eliminate racial disparities in health outcomes by providing training, workforce development, supervision support, mentoring, technical assistance, direct billing, and sustainability planning to community doulas and doula organizations throughout the State of NJ. Thus far, the Doula Learning Collaborative has developed and supported the doula workforce that delivers doula care to NJ's Medicaid and CHIP members as enrolled NJ FamilyCare providers. Since launching, almost 300 community doulas have been trained, with 85 enrolled as FamilyCare providers who have supported over 750 births.

In response to the NJ stillbirth rate that is higher than the national rate, in February 2023, NJ TVP released a Request for Applications (RFA) that seeks to increase awareness of stillbirth prevention measures and decrease New Jersey's high stillborn rate. The selected grantees received \$100,000 to create and implement a Statewide Evidence-based Stillbirth Awareness Campaign that focuses on awareness and prevention measures to reduce New Jersey's high stillborn rate by targeting providers and birthing individuals. In conjunction with New Jersey's Autumn Joy Stillbirth Research and Dignity Act and the selected grantee, NJ TVP is establishing hospital protocols for the care of grieving families. Since launching the Awareness Campaign website, this next year grantees will be hosting regional town halls and possibly adding new language translations, in addition to the five languages represented in stillbirth materials now. The Stillbirth Awareness Campaign aligns with the Nurture NJ Strategic Plan and includes recommendations to reduce NJ's maternal mortality, eliminate racial disparities in birth outcomes, and make New Jersey the safest and most equitable place in the nation to give birth and raise a baby.

The Postpartum Depression and mood Disorders (PPD-MD) program was initiated in 2006 after legislation was created that mandated all pregnant women be screened for PMD after delivery and by their perinatal provider. The focus of the program is to provide postpartum screening in women across NJ to decrease postpartum depression in women after birth. This is being achieved through a streamlined process so that moms can connect with providers within their counties to receive the care they need. Currently, NJ TVP is looking to improve the process by which the calls go through a warmline to provide more efficient care for moms in need of mental health attention after birth.

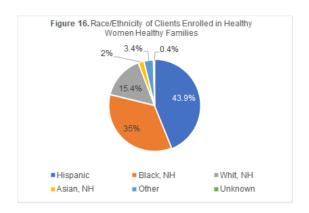
The FASD/Perinatal Addictions Prevention Project grant program serves to increase education and awareness of the risk for FASD, and the risks associated with other prenatal substance exposure. The grant program's main activities are to train and educate private and public prenatal care providers throughout NJ to use the 4p's Plus, or the Pregnancy Risk Assessment, to screen women for substance abuse. The three regional Maternal Child Health Consortia, under the supervision of TVP, are tasked with

providing training and awareness to providers, pregnant persons, and their families. Training and education are delivered via presentations, workshops, and seminars. Social media is also utilized as appropriate to provide consumer education and awareness. To ensure the program's effectiveness, NJ TVP is looking to augment training and the sharing of educational materials for public benefit.

Figure 2. Healthy Women Healthy Families Regions for FY24

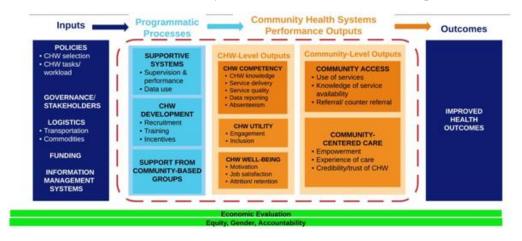


Figure 3. Healthy Women, Healthy Families Race/Ethnicity of Clients



The Alma Program Expansion Project established a new Alma program in NJ that provides new and expectant parents with evidence-based knowledge, skills, and support from peer mentors. The Project seeks to improve maternal mental health and substance use and eliminate racial disparities in health outcomes by program delivery support, an expanded focus on substance use, and program advocacy and stability. The program offers a creative solution to offering care using a peer-to-peer approach. An additional step in this project includes an expansion of the mental health workforce to provide tools that can be locally adapted to meet needs and elevate expertise within communities. The establishment of NJDOH's Colette Lamothe-Galette Community Health Worker Institute (CLG-CHWI) provides training to educate CHWs on 13 core CHW competencies necessary to work effectively with vulnerable populations. Through the CLG-CHWI, CHWs attend 144 hours of relevant classroom instruction over 17 weeks and complete 240 hours of on-the-job training with reflective supervision. The Institute partners with community colleges across the States in Essex, Camden, Mercer, Union, Bergen, Somerset, and Ocean Counties to offer classroom instruction. Through the Rutgers Project ECHO, CHWs were provided with additional training aimed at raising awareness and knowledge on specific health topics, including basics of COVID-19 transmission and prevention, and identifying the impact of COVID-19 in communities where individuals work and live to maintain personal and community safety. Moreover, in late 2023, in collaboration with key stakeholders and CHW instructors who have designed the CHW core curriculum NJ TVP is adding a case management competency to equip CHWs with the skill needed to better case manage their clients. Figure 3 displays an overview of the CHW workforce and the expected outcomes.

Figure 3. Overview of NJ Community Health Worker Workforce and Expected Outcomes



The NJ TVP is taking a targeted approach to improving pregnancy and birth outcomes in the state by enhancing existing programs and creating new programs with an emphasis on this priority population through the CHW Workforce. TVP recognizes the importance of a statewide collaboration of existing traditional and non-traditional partners to address the social determinants of health, which will be instrumental in improving pregnancy and birth outcomes.

As a result, partners from the Department of Labor and Workforce Development, Division of Community Affairs, Department of Education, Department of Transportation, Department of Children and Families, Department of Human Services, Department of Community Affairs, and the Community are strategically collaborating and using MCH block grant funds to implement culturally responsive public health interventions in NJ (Figure 4).

Figure 4. Stakeholder Network



### Child and Adolescent Health Program

In addition to Title V funds, the CAHP currently holds two federal grants to prevent teen pregnancy and promote youth development: (1) the Personal Responsibility Education Program (PREP) and, (2) the Sexual Risk Avoidance Education Project (SRAE). Through PREP, SRAE, and the "Whole School, Whole Community, Whole Child School Health Program" (School Health), CAHP staff operate a statewide youth engagement initiative consisting of 10 Youth Advisory Boards and the NJDOH Voice of Youth Planning Committee. This is managed primarily by the Program Management Officers for School Health, SRAE and PREP with support from the Program Manager.

SRAE is a school, and community-based program focused on building protective factors for youth aged 12-14 to help delay sexual activity and reduce pregnancy and sexually transmitted infections. SRAE uses a Social and Emotional Learning curriculum to provide engagement opportunities, including community service learning, mentoring, and youth leadership. SRAE also utilizes a parent education program employing motivational interviewing techniques to improve parent/teen communication when talking with teens about risks. SRAE is a developmentally appropriate public health approach to sexual health education complementary to the PREP program, which provides extensive education on Sexual Risk Reduction and avoidance. PREP is a school- and community-based comprehensive sexual health education program that replicates evidence-based, medically accurate programs proven effective in

reducing initial and repeat pregnancies among teens aged 14-19. NJ PREP also seeks to help teens avoid and reduce high-risk sexual behaviors through the promotion of delay, abstinence, refusal skills, use of condoms and other forms of birth control, and reducing the number of sexual partners. NJ PREP provides education on the following adult preparation topics: Healthy Relationships, Life Skills, and Adolescent Development. All SRAE and PREP programming is complete, medically accurate, and Lesbian, Gay, Bisexual, Transgender, Intersex, Asexual, and Questioning (LGBTIAQ)-inclusive and trauma-informed. SRAE and PREP programs served 3,049 middle school and high school aged youth in middle schools in New Jersey in 2023. The evidence-based models implemented through these programs include Wyman's Teen Outreach Program, Get Real, NJ Teen Prevention Education Program (PEP) and Love Notes. Each program covers the required sexual health content but varies in delivery to provide some flexibility to schools to address scheduling, content, and student needs.

The Leadership Exchange for Adolescent Health Promotion (LEAHP), a national learning collaborative supporting adolescent health, was established by the National Coalition of STD Directors and Child Trends in partnership with the National Association of State Boards of Education. The NJ LEAHP team was formed in January 2020 and will continue through June 2023 due to delays from the COVID-19 pandemic. Although LEAHP is officially ending, CAHP will continue to use the established multi-sector, state-level leadership team to develop state-specific action plans. These action plans will support policy assessment, development, implementation, monitoring, and evaluation to address adolescent health in three priority areas: sexual health education, sexual health services, and safe and supportive environments. In 2023, the LEAHP committee added youth mental health to the priority areas. The NJ team is led by Jessica Shields, with colleagues from the NJ Department of Education (DOE), NJDOH Division of HIV, STD, TB services, and the NJ Department of Children and Families.

CAHP completed the fifth year of a HRSA grant for Pediatric Mental Health Care Access (PMHCA) which enhanced the existing DCF-administered Pediatric Psychiatry Care Collaboratives, including accessing care via telehealth technology. In October of 2023, NJDOH applied for and received an additional 3 years of funding for the grant. PMHCA aims to improve access to pediatric mental and behavioral health services, which became essential during the COVID-19 pandemic. Key partners include Hackensack Meridian Health, the American Academy of Pediatrics-NJ Chapter, and Rutgers University. Thanks to these partnerships, over 15,678 consultations and referrals, over 2,354 telehealth referrals and 978 face-to-face encounters have occurred, with the 12–21-year-old population most likely to access these services. As of April 2023, 31 pediatric practices, representing approximately 93 providers, have been equipped with telehealth technology through this HRSA grant.

The CAHP is in year four of a five-year Garrett Lee Smith State/Tribal Youth Suicide Prevention from the Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA). The project period ends on 11/29/25, and the award is for \$736,000 per year. Readiness to Stand United Against Youth Suicide: A NJ Public Health Community Initiative Readiness to Stand (NJ R2S Challenge) is a collaborative grant with NJ DCF, the Office of the Secretary of Higher Education, The NJDHS and multiple community-based organizations. In its third year, the New Jersey R2S Challenge has had significant accomplishments, including the launch of the training center on Prevent Suicide NJ https://www.preventsuicidenj.org/online-training/, gatekeeper trainings for youth-serving professionals, education and resources for NJ's County Colleges, the initiation of the third cohort of Lifelines Trilogy in 3 school districts, and 2 youth summits with 263 youth and school professionals in attendance from over 15 school districts across New Jersey. Plans for the coming year include cohort four of Lifelines Trilogy in 3-5 additional school districts, Attachment-Based Family Therapy training for

NJ based behavioral health providers, and the Stanley Brown Safety Plan Training Collaborative Assessment and Management of Suicide Care and the SafeSide® Training for Pediatricians.

Children and Youth with Special Health Care Needs (CYSHCN)

New Jersey's CYSHCN program is known as Special Child Health Services (SCHS). It includes Newborn Screening Follow-up and Genetic Services (NSGS), Early Identification and Monitoring (EIM), Family-Centered Care Services (FCCS), and the newly proposed Data Systems and Emerging Threats Response (DSET) unit. These units include such programs as the Birth Defects and Autism Registry (BDAR), the Early Hearing Detection and Intervention (EHDI) Program, Specialized Pediatric Services Program (SPSP), and the Ryan White Part D program. These programs work as an integrated continuum of care. Figure 5 below highlight some of our 2023 successes.

**Figure 5**. 2023 Special Child Health Services Successes

#### **Newborn Screening and Genetic Services**

Blood Spot Follow Up Critical Congenital Heart Defects (CCHD) Health Services Grants



- 60 years of blood spot screening in NJ (since 1964)
- Followed up on nearly 10,000 out-ofrange results for bloodspot and CCHD
- Health Services grants support 43 specialty programs
- 46 in-services conducted at birthing hospitals
- Establishing a long term follow-up program

#### **Early Identification and Monitoring**

Birth Defects Registry Autism Registry Early Hearing Detection and Intervention

- 8,900+ birth defect and special needs registrations annually
- 53,000+ autism registrations to date
- 99% of all babies received initial hearing screening
- hearing screening

  All registrations connected to case management



### **Data Systems and Emerging Threats Response**

Data Systems Management Emerging Threats Surveillance

- Monitored outcomes for more than 29,000
- Covid-affected pregnancies in 2021-2022
   9,000+ maternal and 9,000+ delivery charts reviewed; 15,000+ well-child visit charts reviewed for Covid outcomes monitoring
- Tracking 300+ syphilis-affected pregnancies delivered in 2018-2022
- Pilot project tracking congenital cytomegalovirus infections
- cytomegalovirus infectionsActive support of all SCHS data systems

#### **Family Centered Care Services**

Ryan White Part D County Case Management Specialized Pediatrics

- 16,873 youth and their families receiving Case Management services at no cost to family
- <1% perinatal HIV infection rate in 2023
- 13 facilities supported by Specialized Pediatrics grants



Newborn Screening and Genetic Services

The NSGS Program ensures that all newborns and families impacted by an out-of-range screening result receive timely and appropriate follow-up services. There are currently 61 disorders screened for on the NJ newborn screening panel. Due to the critical nature of many of the disorders for which NJ newborns are screened, follow-up staff act on presumptive positive results identified by the Newborn Biochemical Screening (NBS) Laboratory for these disorders during regular business hours, Saturdays, and certain State holidays to maximize timely referral to the appropriate specialists. To ensure NJ's program is up to date and effective in terms of screening technologies and operations and responsive to any current concerns regarding newborn screening, the NSGS program staff meet and communicate regularly with several advisory panels composed of parents, physicians, specialists, and other stakeholders. The overarching group is the Newborn Screening Advisory Review Committee and the six established subcommittees (Metabolic and Genetic, Endocrinology, Immunology (SCID), Cystic Fibrosis, Hematology (Sickle Cell Disease), and Neurology.)

The Newborn Screening Follow-Up staff contact primary care providers and specialty care providers to ensure timely evaluation, confirmatory testing, connection to ongoing treatment and care, as needed, and to obtain a final diagnosis. Results received from the NBS Laboratory range from low risk to presumptive positive. Low-risk follow-ups involve sending letters to parents, making telephone calls to physicians and hospitals, and utilizing multiple resources to locate babies for repeat testing.

In calendar year 2023, over 97,000 babies were screened and close to 10,000 abnormal results were received by the follow-up group. From this work, close to 200 children were confirmed to have a disorder from the NJ newborn screening panel. Children with confirmed diagnoses require continued care and in line with State requirements, these children are registered in the BDAR that includes referral to County

level FCCS Case Management services. Additionally, there were approximately 3,500 children identified as likely to be carriers of a disease. These children are not registered in the BDARS, but their families received a letter making them aware of their potential carrier status with recommendations for follow-up testing.

Time for follow-up on low-risk results ranges from two to eight weeks until cases are closed. Time-critical presumptive results require expedient actions to ensure that those babies receive prompt medical intervention and treatment. As per protocol, presumptive cases must be reported to physicians and specialists within three hours of receipt of the result from the NBS Laboratory. However, the NSGS team has averaged approximately 30 minutes to report. Time for follow-up on presumptive results ranges from one week to twelve months until cases are closed. These cases can remain open longer if the complexity of a disorder requires multiple office visits/diagnostic tests to confirm a diagnosis.

The NSGS program applied for and received a State Newborn Screening System Priorities Program (Propel) award; funding opportunity HRSA-23-065 (budget period 07/01/2023 – 6/30/2024, with the potential for a total of five years of funding). This funding has allowed the NSGS Program to begin planning for a Long-term Follow-Up (LTFU) component for the Program. In year one, the team has collaborated with and collected information from multiple states that are further ahead on LTFU for newborn screening. The team plans to use REDCap to manage the LTFU surveys and data collection and has a strong draft survey module created with hopes to begin piloting in early June. The plan is to leverage the already existing FCCS Case Management services to conduct and/or facilitate the annual outreach for LTFU. Many of these children will already be receiving case management services, and their case managers can collect the additional outcome measures. For those who are currently receiving services, the case managers can use the opportunity to contact them for outcome data and to potentially re-engage them as needed.

Since 2011, NJ has mandated newborn pulse oximetry screening to detect Critical Congenital Heart Defects (CCHD). Pulse Oximetry results are captured by NJ's Birth Certificate system and used to identify children at risk for CCHD. Per legislation, any child with a failed pulse oximetry result, is required to be registered in the BDAR. The Newborn Screening and BDAR staff educate hospitals and birth providers about the screening protocol and ensure compliance with the mandates to screen and report.

In 2023, to better understand the pulse oximetry screening data being collected, the population-level screening results from our Vital Events Registration & Information System (VERI) with newly identified CCHD cases was integrated with the BDAR. We established a robust surveillance system to cross-reference our findings. Ultimately, by working collaboratively and integrating systems, we can now better evaluate the complete CCHD screening process in our birthing facilities, including the effectiveness of and adherence to the screening algorithm. The goals were to validate that all failed screenings were registered, that the children received appropriate follow-up, and that any subsequent diagnoses were reported.

In 2023, The VERI system indicated that 105 newborns had failed Pulse Oximetry values. Our team reviewed these and confirmed that 15 of these were data entry errors. Thus 90 newborns had confirmed failed values. Of these, 11 were registered with a CCHD and 16 were registered with another cardiac condition. Forty-six were evaluated and no cardiac condition was diagnosed. Upon review, four newborns met the criteria for "saved" which meant that had they not received the screening, they may

have been discharged without evaluation. The screening mandate was enacted to prevent healthypresenting babies being discharged only to become critically ill later.

The CCHD program continues to collaborate with BDAR staff on Component C of a Cooperative Agreement with the Centers for Disease Control and Prevention's (CDC) (Advancing Population-Based Surveillance of Birth Defects; CDC-RFA-DD21-2101). Component C focuses on the timing and method of CCHD detection. To improve data quality, BDAR, and pulse oximetry screening staff collaborated to have new fields added to the BDAR pulse oximetry/CCHD module. The new fields went live in mid-January 2023. The new fields help satisfy the requirements of the CDC project and provide an enhanced picture of pulse oximetry screening follow-up in NJ.

### Early Hearing Detection and Intervention (EHDI)

The NJ EHDI Program abides by the national public health initiative "1-3-6 Guidelines." These guidelines seek to ensure that all babies born in New Jersey receive a newborn hearing screening before one month of age, complete diagnostic audiologic evaluation prior to three months of age for infants who do not pass their hearing screening and enroll in early intervention by no later than six months of age for children diagnosed with hearing loss. The EHDI program offers technical support to hospitals on their newborn hearing screening and follow-up programs.

New Jersey hospitals are very successful in ensuring newborns hearing screening, with 99% of babies screened. However, receiving timely and appropriate follow-up remains an area needing improvement, with 87% of children who did not pass initial hearing screening being documented as receiving follow up in 2022. New Jersey EHDI works with health care providers, local and state agencies that serve children with hearing loss, and families to ensure that infants and toddlers receive timely hearing screening and diagnostic testing, appropriate habilitation services, and enrollment in intervention programs designed to meet the needs of children with newly identified hearing loss.

#### Specialized Pediatric Services Program (SPSP)

The SPSP aims to provide access to comprehensive, coordinated, culturally competent pediatric specialty and sub-specialty services to families with CYSHCN that are 21 years old or younger (Figure 7). With support from the State and Title V funds, health service grants are distributed to multiple agencies throughout NJ. The SPSP consists of eight Child Evaluation Centers (CECs), of which four CECs house FASD Centers, and three CECs provide newborn hearing screening follow-up. Additionally, there are three Pediatric Tertiary Care (PTC) Centers and five Cleft Lip Cleft Palate-Craniofacial (CLCPC) Centers. All centers provide services statewide across the 21 counties in New Jersey and are partially funded via the health service grants. In SFY23, there were a total of 84,149 patients served across all centers within the Specialized Pediatric Services Program. Of these, 48% (41,094) of children were served at the CECs, 2% (1,350) at the CLCPCs, and 50% (41,705) at the PTCs. Approximately 58% of the children served are uninsured or are covered via Medicaid/Medicare programs. In SFY23, \$2,205,025 was awarded to CEC grantees, while \$770,392 was distributed to CLCPCs and \$933,071 to PTCs.

Figure 6. Specialized Pediatric Centers



Birth Defects and Autism Registries (BDAR)

Since 1928, New Jersey has been reporting birth defects and has the longest tenure of any state for these reporting requirements. Over the years, our BDAR has become a robust population-based registry for children with birth defects and autism spectrum disorders and provides invaluable surveillance and needs assessment data for service planning and research. All 47 birthing hospitals and hundreds of non-hospital-based practices report to the BDAR through our online registry. Annually, we receive an average of 4,700 birth defect registrations and 3,700 autism registrations. In 2021, the Birth Defects Registry expanded its case ascertainment efforts by abstracting charts of New Jersey children with birth defects who were born at, transferred to or diagnosed by the Children's Hospital of Philadelphia (CHOP). This was an important step forward as these children have complex health care needs and, with this connection, would receive both surveillance of the birth defects in tandem with case management services. We anticipate future agreements with other border state hospitals so that more children will be included and served.

The BDARS has been redesigned to include a statewide pre-registration search feature to reduce duplication of records, reduction of questions, and easier to use checkoff lists for common comorbidities, symptoms, and behaviors. As NJ has the statutory authority to capture fetal deaths due to birth defects at 15+ weeks of gestation, a new module has been implemented to capture and report these fetal deaths to the CDC. The EIM staff continues to educate providers about the BDAR, how to register, and the rules regarding the Registry. Staff creates reports and resources for both providers and families. These continuous efforts and changes will improve our data's accuracy and overall surveillance efforts.

Beginning in 2009, the NJ Autism Registry is the largest mandated autism registry in the country, with more than 52,000 total registrations. Each year, health care providers submit between 3,000 and 4,000 new registrations. It is the only registry in the country that includes children up to the age of 22 and refers them to their local country case management services. We serve as a model registry and continue to provide technical assistance to other states considering a registry.

The Autism Registry provides quality prevalence information for the entire state (Figure 7) and can provide information by demographics, including by race and ethnicity. Current national studies such as the Autism and Developmental Disabilities Monitoring (ADDM) Network estimate that the rate of autism in New Jersey is 1 in 34 (based on review of records of a cohort of 8-year-old children in four counties who meet criteria for autism). The Autism Registry, which calculates its rates based on children in every county who has been diagnosed and registered by a health care provider, has shown similar prevalence rates. In 2023, Autism Registry staff performed analytics on total autism rates and other metrics for each NJ county as compared to the state overall. Staff used these data to create a snapshot or profile of registry data for each of the 21 counties in NJ. Some counties show a higher prevalence rate than the State overall, while some are lower. Other metrics examined include presence of known perinatal risk factors (low birth weight, multiple birth, and maternal age >35) for children with and without autism in each county compared to children with and without autism in the State overall. The profiles include the average age at which a child is diagnosed in a county compared to the State and examine the percentage of children who were able to receive a diagnosis in the county where they reside or if they had to travel elsewhere (compared to the State overall). The profiles were developed to help families learn more about autism in their communities and the resources available to them, and to help county level public and private agencies plan for programs and services for people with autism.

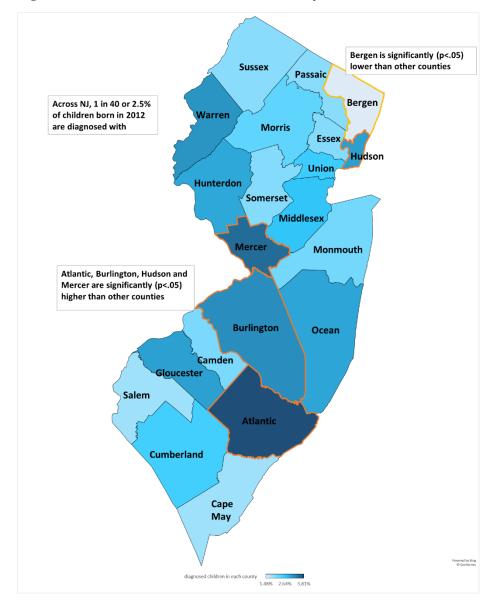


Figure 7. Prevalence of Autism Across New Jersey

As seen in the figure below, not only is there an increase in the prevalence of autism over time, but we see that the race/ethnicity differences are reducing for the most recent birth cohorts. This narrowing of autism rates by race and ethnicity is potentially due to expanded services, more multilingual professionals, and a strong family education program such as the CDC's Learn the Signs, Act Early program.

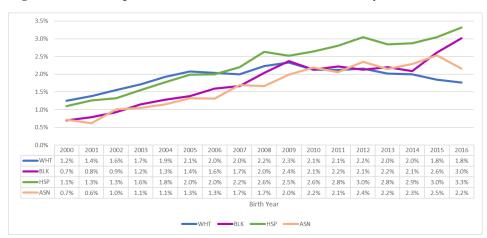
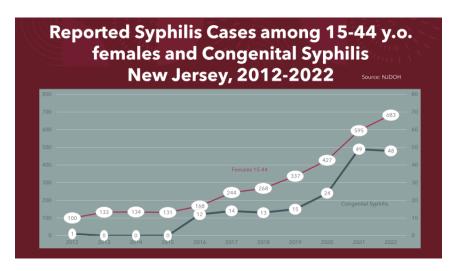


Figure 8. Autism Spectrum Disorder Prevalence Over Time by Birth Year

# Data Systems and Emerging Threat (DSET) Response

An important function of SCHS is to identify and respond to trends in exposures to pregnant persons that have the potential to fuel rising rates of children with special health needs. Between April 2020 and August 2023, the SCHS work in this area included monitoring outcomes of pregnancies complicated by COVID-19 infection. The program worked collaboratively with partners in Communicable Disease Services and in Population Health to identify over 25,000 infections during pregnancy. The program scaled up staff with funding from CDC's Surveillance of Emerging Threats to Pregnant People and Newborns (SET-NET) program used existing program staff and additional temporary staff to review maternal, newborn, and well child visit charts and report de-identified data to CDC. Over 9,100 delivery hospital records and well child visit records for over 9,200 children were reviewed with data elements of interest abstracted. The COVID project ended in July 2023 because of declining infection rates. However, the SET-NET project was expanded in August 2022 to include surveillance of congenital syphilis and congenital cytomegalovirus (cCMV) infections. Syphilis infections during pregnancy and cases of congenital syphilis have been rising significantly in New Jersey and nationally.

Figure 9. Reported Syphilis Cases



By July 2023, the project had identified 314 pregnancies with delivery outcomes in 2018-2021 that were complicated by syphilis infection and maternal/newborn chart abstraction was complete on 85% of those cases. Beginning in July 2023, Staff are tracking the infants with congenital syphilis through age two and abstracting data from their well-child visit charts. During SFY23, the CMV project completed case ascertainment from several data systems and requested medical records for 132 pregnancies with chart review for those cases starting in FY24. The DSET program is looking at strategies to identify additional exposures appropriate to this model.

### Family-Centered Care Services (FCCS)

FCCS Special Child Health Services Case Management (SCHSCM) oversees and provides approximately four million dollars in funding to 21 county-based CMUs. These funds include federal and state MCH Block grants, Casino-revenue, and Catastrophic Illness in Children Relief funds. CMUs also receive funds from their county governments. These units provide resources and referrals to families of children from birth up to their 22nd birthday. Annually, over 84% of families opt into case management services with SCHSCM, which totals about 16,800 families. The diversity of NJ is seen in the children and families served by the CMUs. The race/ethnicity breakdown for children served in SFY23 is 38.1% Hispanic or Latino, 38.1% White, 14.9% Black or African American, 6.1% Asian/Pacific Islander, and 2.8% Other Races.

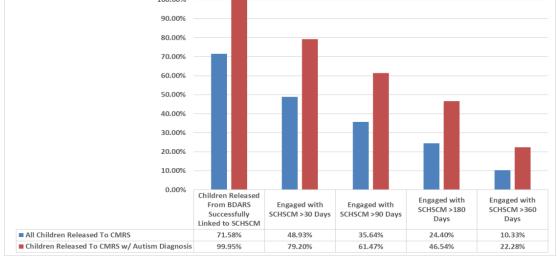
FCCS plays a central role in ensuring that all counties provide robust services and collect key information to establish quality and equity across New Jersey. SCHSCM staff also educates all CMUs about relevant federal, state, and community partners. FCCS's ongoing intergovernmental and interagency collaborations include, but are not limited to, the Social Security Administration, NJ Department of Children and Families, Department of Banking and Insurance, the Boggs Center/Association of University Centers on Disabilities, NJ Council on Developmental Disabilities, and community-based organizations such as Autism NJ, New Jersey Chapter, American Academy of Pediatrics (NJAAP), NJ Hospital Association, and the disability-specific organizations such as the Arc of NJ, SPAN Parent Advocacy Network, and the Statewide Community of Care Consortium (COCC). Consultation and collaboration with NJDOH's other DOH programs such as NJEIS, Ryan White Part D, MCH, Women, Infants, and Children (WIC), FQHCs, HIV/AIDS, Sexually Transmitted Diseases and Tuberculosis, as well as Public Health Infrastructure Laboratories, and Emergency Preparedness affords FCCS with opportunities to communicate and partner in supporting CYSHCN and their families.

The CMUs remain successful in linking CYSHCN to important services. Below is a summary of a child and her family's journey navigating her various needs over the past decade, thus showcasing the role of CMUs working with Title V-CYSHCNs.

Reflective Quote: When the child began struggling in public elementary school, the CM helped get the child out of district placement where she's been receiving a great education for the past 12 years. Mom passed away a few years later so the CM started working with Dad very closely to meet several of her educational needs, respite care, and transition to adulthood needs regarding guardianship. The student is now registered with DDD, has Medicaid, and is receiving services through the personal preference program. She has been accepted at the day program of the family's choice and will be a June 2024 graduate with all her adulthood services in place.

One key factor that FCCS focuses on for SCHSCM is the level of engagement with children referred to the Case Management Referral System (CMRS) from the BDARS. The figure below illustrates the level of family engagement within SCHSCM. The special needs population at large has a diverse level of need. For example, comparing a child born with hypospadias, which can be surgically corrected and require no further assistance from a CMU to a child with a diagnosis of moderate hearing loss, who may have a greater and prolonged level of need, results in a greater level of engagement. Families that SCHSCM are unsuccessful in contacting explain why CMUs have only connected with 71.58% of the children and families released from BDARS. Children with more complex or comprehensive conditions, such as autism, successfully link and remain engaged for a greater amount of time after their initial linkage to SCHSCM. By comparison, children with autism released from BDARS to SCHSCM successfully link 99.95% of the time. Of those children, 22.28% remain engaged for more than 360 days from their initial linkage compared to 10.33% of all children (Figure 10).

Figure 10. Level of Engagement for Children Linked to Special Child Health Services Case Management After Release From BDARS



SCHSCM staff focus on continuous quality improvement (CQI) initiatives. One major endeavor is the redesign of the CMRS which will greatly improve the data gathering capability and enhance consistency in documentation within Individual Service Plans (ISPs) across the CMUs. All 21 CMUs use CMRS to track and monitor services. CMRS provides the ability for CMs to create and modify an ISP, track services, referrals, linkages to care, document each contact with the child and the child's family, and

register previously unregistered children. Additionally, the ISP provides the State Title V program with the opportunity for desktop audits, the ability to track access to care, and ensures more measurable and readily tracked outcomes.

Additionally, FCCS manages a Fee-for-Service program that assists eligible New Jersey families to purchase hearing aids, orthotics, or prostheses through a State approved vendor system. Family cost participation is calculated using a sliding scale based on family size and income, and the SCHSCM case managers support families in completing the application process. Since Grace's Law was passed in 2008, requiring NJ insurance companies to cover medically necessary expenses incurred in the purchase of hearing aids for children under the age of fifteen (15), most children served by this program are NJ children who do not have NJ-based health insurance plans or any health insurance coverage at all.

SCHS also refers children ages birth to three to the New Jersey Early Intervention System (NJEIS), which serves the developmental and health-related needs of eligible children. Early intervention services are designed to address a problem or delay in development as early as possible. NJEIS provides quality services in a child's natural environment (settings in which children without special needs ordinarily participate and that are most comfortable and convenient for the family) by enhancing the capacity of families to support their child and creating a partnership between practitioners and families. Early intervention aims to promote the child and family's ability to meet developmental outcomes chosen by the family and outlined in the Individualized Family Service Plan. The system serves approximately 30,000 families annually and provides approximately 40,000 service hours per month. NJEIS provides several services, some of which are: occupational, physical, and speech therapy, as well as developmental intervention. NJEIS is a fee-for-service program and operates with Family Cost Participation charges based on a sliding scale.

Commitment to eliminating health inequities while centering the voices of people with lived experiences.

Throughout the state's MCH programming, a commitment to eliminating inequities in service provision and elevating the voices of those with lived experience is evidenced by the expansion of programming throughout the state, with a specific focus on families who are not connected to health care, impoverished, and speak languages other than English. Recognizing the importance of parent/consumer involvement through focus groups in designing and implementing a program to address preterm births and infant mortality issues, the MCH Program incorporated focus groups into several programs under the HWHF initiative, including those for doulas, breastfeeding, and addressing disparities. The HWHF grantees have also established Community Advisory Boards with an emphasis on recruiting new and nontraditional partners. Similarly, the MIECHV also requires funded grantees to implement County Advisory Boards. Our Alma project hires peer mentors throughout the state who have lived experience as parents with postpartum depression or substance use, and who speak Spanish. Providing doula support and home nursing support to all NJ birthing people during pregnancy and postpartum demonstrates the commitment we have to individuals in the perinatal period, and to reaching those with greater needs. Additionally, the state continues to cultivate a strong connection to local agencies like the SPAN Parent Advocacy Network, a program that helps to elevate parent and family voices. Our preterm birth prevention program is working to ensure that birthing people with high perinatal morbidity events are receiving services rooted in best practice methodologies. Moreover, the state has invested additional funds into workforce development, prioritizing of hiring people from the community with characteristic parity to the recipients of our programming.

#### III.C. Needs Assessment

### FY 2024 Application/FY 2022 Annual Report Update

For the interim needs assessment update, NJ TVP compiled and synthesized statistics seeking to inform the current maternal and child health interventions that MCHBG is funding. The Team has compiled data from multiple sources, including but not limited to the American Community Survey, New Jersey Pregnancy Risk Assessment Monitoring System (PRAMS), World Health Organization (WHO), Centers for Disease Control (CDC), and more.

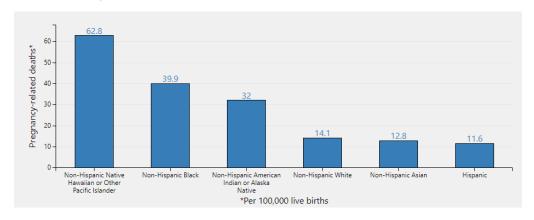
Other, local, needs assessments have been conducted in NJ to get a contemporary conceptualization of the characteristics and dynamics of communities served. In 2022, the University Hospital (UH) in Newark examined both primary and secondary data to better understand the complex health issues facing patients from their core service areas (CSAs). Four, core focus areas guided the research, and included information on key characteristics of people who access services at UH, their health status, the interplay between community characteristics and health status, and the best ways that data can drive decision making in the UH system of care. The findings revealed correlations between social determinants of health (SDOH) and chronic diseases and recommendations for prevention and intervention efforts aimed at the most impoverished patients from the CSA. In the same year, the Trenton Health Team conducted a needs assessment in Trenton to determine community health priorities. Using quantitative and qualitative data methodologies, the respondents reported that mental health issues, maternal and child health issues, equitable access to preventative clinical treatment and COVID-19 management. These data also proved helpful in informing programmatic focus areas for the upcoming strategic planning cycle.

Maternal & Women's Health, Reproductive Health, & Perinatal/Infant Health

### Maternal Mortality

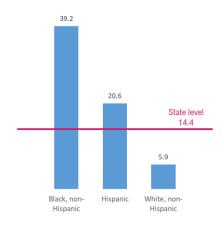
According to the <u>CDC's Pregnancy Monitoring and Surveillance System (PMSS)</u>, the 2019 pregnancy-related mortality ratio (PRMR) in the US was 17.6 deaths per 100,000 live births in the US. When stratified by race/ethnicity, evident disparities persist. Native Hawaiian/Pacific Islander NH and Black NH women had PRMRs of 62.8 and 39.9 deaths per 100,000 live births, respectively, from 2017-2019. The Black NH PRMR was more than three times the rate for White NH women (12.8 deaths per 100,000 live births, Figure 11). Additionally, Hispanic women had the lowest PRMR among all races/ethnicities nationally, with a rate of 11.6 deaths per 100,000 live births.

**Figure 11.** U.S. Pregnancy-Related Mortality Ratio by Race/Ethnicity, 2017-2019 (Pregnancy Mortality Surveillance System)



The NJ Maternal Mortality Review Committee (NJMMRC) reviews all pregnancy-related and pregnancy-associated deaths among NJ residents during pregnancy or within one year of the end of pregnancy. 2016-2018 data from the NJMMRC confirm persistent racial and ethnic disparities regarding maternal mortality. The NJMMRC identified 44 pregnancy-related deaths, of which 39/43 (91%) were determined to be preventable. The state-level pregnancy-related mortality ratio for 2016-2018 was 14.4 deaths per 100,000 live births; however, similarly to national PMSS data, disparities are evident among race/ethnicity. Figure 12 shows the PRMRs by race/ethnicity. The PRMR for Black NH women was 39.2 deaths per 100,000 live births, which was 6.6 times higher than the PRMR for White NH women, which was 5.9 deaths per 100,000 live births Hispanic women had a PRMR (20.6 deaths per 100,000 live births) 3.5 times higher than White NH women.

Figure 12: Pregnancy Related Mortality Ratio by Race, 2016-2018



Source: New Jersey Birth Certificate Database, Office of Vital Statistics and Registry, NJDOH; New Jersey Maternal Mortality Review Information Application (MMRIA)

Based on the analysis conducted by the MMRC, the leading contributing factors for *pregnancy-related deaths* were lack of provider/patient knowledge, lack of continuity of care/care coordination, lack of standardized policies and procedures, substandard clinical skill/quality of care, and lack of assessment. While the leading contributing factors for *pregnancy-associated but not related cases* were lack of continuity of care/care coordination, complications of substance use disorder, complications of mental health conditions, lack of provider/patient knowledge and lack of standardized policies and procedures. The MMRC made an array of recommendations categorized into 5 themes by classes of maternal mortality, emphasizing actions that providers and facilities could take to identify and potentially address maternal mortality disparities. For each class, these were:

Pregnancy-related deaths:

- Ensure high-quality care,
- Build patient knowledge,
- Address barriers to care,
- Implement a holistic approach to care and
- Share patient records and information about care provided.

### Pregnancy-associated but not related deaths:

- Implement a holistic approach to care,
- Ensure high-quality care,
- Address barriers to care, and
- Share patient records and information about care provided.

### Severe Maternal Morbidity

In 2022, New Jersey's total SMM with transfusion rate was 227 per 10,000 delivery hospitalizations, and SMM without transfusion rate was 67 per 10,000 delivery hospitalizations. As with pregnancy-related mortality, racial and ethnic disparities are substantial and persistent in severe maternal morbidity. Black NH women giving birth in New Jersey suffered the greatest burden of preventable morbidity, with racial disparity in rates present and growing since 2011. In 2022, Black NH women suffered the highest SMM rates (385 per 10,000 delivery hospitalizations). The rate for White NH mothers is the lowest at 163 per 10,000 delivery hospitalizations (Figure 13). The 2022 leading causes of severe maternal morbidity in New Jersey per 10,000 delivery hospitalizations were: acute renal failure (18.5 per 10,000 delivery hospitalizations, and shock (8.4 per 10,000 delivery hospitalizations).

Figure 13: Severe Maternal Morbidity by Race/Ethnicity, New Jersey, 2011-2022



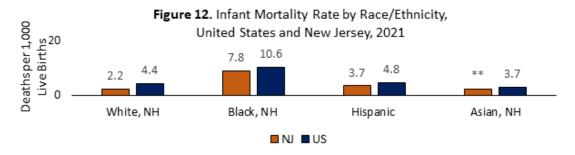
### Infant Mortality

According to America's Health Rankings, as of 2021, New Jersey has the 3rd lowest overall infant mortality rate among the 50 states; however, similarly to the racial and ethnic disparities observed nationally, these disparities persist.

CDC data from the <u>National Vital Statistics System</u> identified that in 2021, racial and ethnic disparities in infant mortality continued to persist in the US among Black NH women, who had the highest IMR (10.6) per 1,000 live births, followed by Native Hawaiian or Other Pacific Islander NH (7.76), American Indian or Alaska Native NH (7.46), Hispanic (4.79), White NH (4.36), and Asian NH (3.69) (Figure 14).

In 2021, NJ's Black NH infant mortality rate (IMR) was 7.8 per 1,000 live births, while the IMR for White NH infants was 2.2 per 1,000 live births (Figure 14). The Hispanic IMR was also 3.7 per 1,000 live births. The Black NH IMR was nearly four times higher than the IMR for White NH infants, and the Hispanic IMR was nearly two times higher than the rate among White NH infants in NJ. Findings from the most recent 5-year needs assessment include the need to address NJ's maternal mortality crisis and disparities seen in both maternal and infant mortality rates These statistics warrant the need to continue implementing public health interventions that seek to address these racial and ethnic disparities and improve maternal and child health outcomes in NJ.

Figure 14: Infant Mortality Rate by Race/Ethnicity, United States and New Jersey, 2021



Source: National Data (National Center for Health Statistics, National Vital Statistics System); New Jersey (Office of Vital Statistics and Registry)

Key Demographics among Delivery Hospitalizations

According to a review of NJDOH's Vital Statistics and Registry data:

- In 2022, 96,844 delivery hospitalizations occurred in New Jersey.
- 34,547 delivery hospitalizations during this time were considered NTSV-Cesarean births, where NTSV is defined as: nulliparous (first-time mother); term (37 weeks' gestation or above); singleton (one fetus); vertex (head-first presentation).

Among 2022 delivery hospitalizations, the following racial/ethnic stratifications were:

- White non-Hispanic (NH): 45%
- Hispanic women: 30%
- Black NH: 12%
- Asian NH: 10%
- Other/Multi-Race, NH: 3%

64% of delivery hospitalizations were financed through private insurance, 32% through Medicaid, 3.9% through either Self-Pay or Charity Care, and 0.1% other.

In 2022, 71% of all delivery hospitalizations were by women who initiated prenatal care during the first trimester; however, when stratified by race/ethnicity, first trimester prenatal care initiation was lowest

among Hispanic (58%) and Black NH (59%) women, while it was highest among White NH women (81%). When assessing medical conditions at the time of delivery, 12.3% of New Jersey mothers had either chronic/gestational diabetes, while 9.9% had chronic/gestational hypertension, both of which are an increase from 2016, where diabetes prevalence was 9.8% and hypertension prevalence was 8.2%. When assessed by race ethnicity, diabetes prevalence was highest among Asian NH women (22.5%) and hypertension prevalence was highest among Black NH women (16.4%).

#### Preterm Birth

Preterm live births are <u>defined as</u> the birth of an infant before 37 weeks of gestation. Being born prematurely increases an infant's risk of morbidity and mortality. Premature infants have a greater risk of dying in the first month of life, may require intensive care at birth, and are at higher risk of developmental disabilities and chronic illnesses throughout life.

Nationally, in 2020, disorders related to preterm birth and low birth weight accounted for about 16% of infant deaths before their first birthday. Based on statistics provided by the CDC, 1 of every 10 infants in the US was born prematurely in 2021. An increase of 4% in the preterm birth rate was observed nationally from 2020 to 2021 (10.1% to 10.5%, respectively). In 2021, while an increase was observed nationally, NJ's preterm birth rate dropped from 9.3% to 9.2%, respectively. An 8% dropped in preterm rate is observed in NJ from 2016 to 2021, while a 7% increase is observed nationally for the same period. Although declining in New Jersey, these statistics on pre-term births warrant the need to continue implementing public health interventions to sustain or improve these maternal and child health outcomes.

#### Access to Care

The following data from the 2021 NJ Pregnancy Risk Assessment Monitoring System (PRAMS) address the access to care data deliverables for State Maternal Health Innovation Program (SMHIP). NJ PRAMS is a joint project between NJDOH, CDC, and the Rutgers University Bloustein School. Women as defined in this data set include mothers who are residents of New Jersey who delivered within New Jersey a liveborn infant during the surveillance period (calendar year 2021).

Percentage of women covered by health insurance, 2021			
	Medicaid	Private insurance	No insurance
Before pregnancy	20.50%	64.30%	15.20%
For prenatal care	31.30%	63.70%	5.00%
For delivery	32.80%	62.00%	5.20%
Postpartum	27.30%	61.60%	11.10%

Percentage of women who receive an annual well-woman visit:

65.7% of women reported having any health care visits with a doctor, nurse, or other health care worker (including a dental or mental health worker) in the 12 months before getting pregnant with their new baby. Among those women that reported having a health care visit in the 12 months prior to getting pregnant, 52.4% had a regular checkup at their family doctor's office. 33.9% reported having a regular checkup at their OB/GYN's office.

Percentage of pregnant women who receive prenatal care:

98.6% of women receive prenatal care as of 2021, however in 2017, according to birth certificate data 1,550 women delivered a newborn in NJ without receiving a single prenatal care visit. 83.4% percent of women received prenatal care in the first trimester, and 90.4% percent of women received a postpartum visit.

Among women screened for perinatal depression in 2021, during prenatal visits, 69.1% of women were asked if they were feeling down/depressed and during postpartum visits, 85.6% of women asked if feeling down/depressed.

# Formative Evaluation Projects & Results

In the past few months, NJ TVP has led multiple projects to assess the needs of the MCH population in NJ.

### Community Health Worker Evaluation

In collaboration with the Rutgers School of Public Health, NJ TVP developed an evaluation project that focuses on examining the adopted strategies used to train, deploy, and engage CHWs. The priority trainee populations include racial and ethnic minority groups, immigrants, those with limited English proficiency, the homebound, seniors, the homeless, disabled populations, migrant workers, pregnant and nursing mothers, the underinsured and uninsured, undocumented workers, and people with substance use disorder diagnoses. The evaluation found that CHWs overall are highly satisfied with the training they receive and their jobs; however, compensation and job security are potential areas of improvement for retaining CHWs over the long run.

The evaluation project aided NJ TVP in assessing the effectiveness of the CLG-CHWI and Rutgers Project ECHO training on increasing CHW competencies and improving curricula materials and instruction to address gaps in training. Based on the evaluation project results, NJ TVP is working on further updating the curricula and assessment materials to better equip CHWs with the skill needed to serve their clients adequately. NJ TVP and evaluation partners are also using results to assess progress and improve strategies for recruitment and deployment to optimize CHW integration into community organizations and to address and support the integration of CHWs within diverse organizations.

Fetal Alcohol Syndrome Prevention and Postpartum Depression and Mood Disorders- Evaluation Project

In 2001 the Fetal Alcohol Syndrome Disorder (FASD) Taskforce comprised representatives from the NJ Department of Health (DOH) recommended steps to expand prevention programs and strengthen systems to alleviate the effects of prenatal alcohol exposure in NJ. The NJ DOH funded multiple grantees to implement FASD-related activities that seek to reduce the impact of prenatal exposure to substances in NJ communities.

The NJ Postpartum Depression and Mood Disorders Initiative was established by former Governor Codey in July 2005 to raise awareness about postpartum depression and to increase access to appropriate clinical services. Through this initiative, NJ TVP, through the grantees it funds, seeks to provide information about symptoms, screening, diagnosis, and treatment of postpartum depression to healthcare providers and New Jerseyans. PPD-MD grantees outreach to women and their families via a toll-free hotline, brochures, and online resources.

In 2023, over 20 years after the implementation of the FASD program and over 15 years after the implementation of the PPD-MD program, the NJ TVP Epidemiology Team designed and conducted an informative evaluation project to inform future programmatic and policy efforts. The evaluation projects had multiple phases corresponding to key project activities. Phase 1 involved compiling maternal and child health-related statistics, formulating the evaluation questions, selecting the methodological approach, designing the surveys, and the initial recruitment for the project. Phase 2 involved administering online surveys through the Novisurvey platform and hosting a listening session with the grantees. Phase 3 involved data analysis of survey responses, hosting one listening session, and the write-up of results and recommendations.

As a result of the formative evaluation project, NJ TVP Epidemiology Team generated a comprehensive list of culturally competent recommendations grouped into four categories:

- 1) System Level,
- 2) Programmatic Level,
- 3) Data-related, and
- 4) Material Development or Revision

The evaluation results led to a complete revision of the PPD-MD program goals and objectives and the launch of a new Request for Applications in Spring 2024. The FASD program will similarly be revised in SFY25.

#### Adolescent Health

The CAHP collects pre- and post-survey data for all students who participate in our programs (with parental consent). The following are data collected in the prior program year related to social-emotional learning and bullying prevention.

After completing a PREP evidence-based model (EBM), students reported the following:

- 82% indicated they were more/much more able to manage emotions in healthy ways
- 75% indicated they were more or much more able to resist or say no to peer pressure
- 77% indicated they were more or much more likely to talk with a trusted adult/person (for example parent, family member, teacher, counselor, etc.) if someone makes them feel uncomfortable, hurts them, or pressures them to do things they don't want to do

After completing a SRAE EBM, students reported the following:

- 67% indicated they were more or much more able to manage their emotions in healthy ways
- 72% indicated they were more or much more able to resist or say no to peer pressure
- 69% talked to a trusted person/adult if someone makes me feel uncomfortable, hurts me or pressures me
- 81% felt respected as a person while participating in SRAE programming

After completing the Teen Outreach Program (TOP®) (specifically), students reported the following:

- 92% indicated they were able to make decisions to keep themselves healthy and safe (5% increase)
- 83% indicated they were able to come up with ways to solve problems (16% increase)
- 91% indicated they were able to understand how other people feel (9% increase)

- 85% indicated they were able to help make their community a better place (21% increase)
- 88% indicated they could handle the challenges that came their way (11% increase)

Students receive a pre- and post-survey provided by the funder (Family Youth Services Bureau) that covers all EBMs implemented. Students who participate in TOP® specifically receive an additional pre- and post-survey developed by the model developer. The above data shows how students who participated in our programs had increased skills and protective factors related to social-emotional learning and bullying prevention.

## Children and Youth with Special Health Care Needs (CYSHCN)

A targeted Quality Assurance (QA) Audit initiative for all SPSP grantees commenced in 2023 and continued through February 2024. Grantees provided the DOH with patient and visit counts for SFY23, which were then deduplicated. The goal of this review is to better understand the utilization patterns and identify program overlap/potential gaps in services. SCHS SPSP staff ascertained that required quarterly Progress Reports have not been interpreted uniformly across grantees, despite detailed instructions. The QA shed light on the mediocre systems many grantees utilize to capture reported data, ranging from manual counting to pulling data from three internal systems and doing their best to synthesize the data. This information has spurred the SPSP team to further analyze the content of the progress reports and help grantees justify the need for improved data systems from their parent organizations.

In 2022, FCCS conducted a pilot satisfaction survey of families registered with SCHSCM for continuous quality improvement. The results showed that 79% of responders felt their SCHS case manager supports their family, and 77% said their CM meets the needs of their family. Additionally, over 65% of responders ranked the overall value of SCHSCM services as either excellent or very good. As a result, in 2023, SCHSCM staff has incorporated an acuity tool and SMS text messaging into the redesign of the electronic data system, that will be able to enhance communication with the families served by SCHSCM and conduct annual and exit satisfaction surveys. The data will help to continuously identify areas of improvement and guide policy and implementation of SCHSCM services across the State.

SCHSCM utilizes the Case Management Reporting System as its primary hub to document all case management activities. These include communication with affected families, individual service plans, case management actions, service delivery, deactivations, and more. Currently, CMRS is undergoing a major redesign that will enable the capturing of data to monitor and evaluate the services provided to CYSCHN populations. The redesign encompasses several modules of the system, including Individual Service Plan, Exceptional Events, Child Information, custom reports at the CMU level, the ability to conduct family surveys, and features that will better facilitate communication with families.

### NJ's Ongoing Needs Assessment Activities

NJ is currently engaging in the five-year grant cycle needs assessment process. Several initiatives are occurring simultaneously to better understand how Title V funding is distributed throughout the state, while examining impact of activities and voids to be addressed. One initiative that has been organized is an internal Work Group that discussed data sources, presents on programmatic strengths and growing edges and proposes ways to move forward with program modifications. Concomitantly, a Steering Committee of professional stakeholders from the clinical, governmental, non-profit and parent advocacy arenas has been created to offer feedback and liaise between service recipients and the TVP in gathering information regarding Title V programming in NJ. During the summer of 2024, public health interns will be working with the TVP to facilitate focus groups with families and community members with lived

experience, as well as conduct key informant interviews with clinical practitioners and other stakeholders, to further understand perspectives on the Title V programming in NJ. As these feedback initiatives are occurring, TVP staff are discussing ways to implement best practices in performance monitoring and assessment of the activities.

#### **III.D. Financial Narrative**

III.D.1 Expenditures---To be completed with updated numbers by July submission

III.D.2 Budget---To be completed with updated numbers by July submission

III.E. Five-Year State Action Plan

III.E.1. Five Year State Action Plan Table

**State: New Jersey (attachment)** 

III.E.2. State Action Plan Narrative Overview

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

The NJ Title V Program (TVP) is uniquely positioned through its leadership and robust partnerships with families, healthcare organizations and other local, state, and federal entities, to address healthcare needs of all mothers, children, and adolescents in the state. The NJ TVP has continued to grow and strengthen with the advent of new and innovative programs, and with the enhancement of the programs already in place. The TVP facilitates collaboration and partnership with state agencies and organizations including the SPAN Parent Advocacy Network, the NJ Chapter of the American Academy of Pediatrics, the NJ Hospital Association, the state's Maternal and Child Health Consortia and other local non-profit and community-based organizations. NJ TVP is committed to advancing creative and evidence-based solutions to the complex health issues facing mothers, infants, and children across the state, with a particular focus on children with special health care needs. NJ's commitment to the state's maternal and child health populations is unwavering and continues to fortify as evidenced by its expanded, strategic programming and partnerships.

While NJ has invested resources to address the maternal and child health crises that exist in the state, the proposed plans will take time to produce results. New Jersey continues to experience high rates of maternal mortality and morbidity events and deaths, disproportionately impacting women, and children of color. The continued efforts promote the health and well-being of families across the state, with an acute focus on the populations on the margins and at highest risk of experiencing preventable morbidity and mortality events and deaths. With continuous fiscal and political state support, New Jersey is in a strong position to improve on MCH work being done and engage in innovative endeavors that complement and enhance the services being provided.

One of the initiatives that has grown in reach over the period of the past calendar year is the Healthy Women, Healthy Families (HWHF) Initiative. This initiative works toward improving maternal and infant health outcomes for women of childbearing age and their families while reducing racial, ethnic, and economic disparities in those outcomes through a collaborative, coordinated, community-driven approach. This coordinated approach uses CHWs (to complete clinical and social needs assessments) and

Connecting NJ Hubs, or county-specific "points of entry," for clinical assessments. Referrals and tracking occur through a central data management platform. To improve upon this innovative endeavor, HWHF re-launched in 2023 with a renewed focus on CHW and postpartum doula support, with doula care expanding to serve postpartum birthing people for the first 12 months after delivery, including breastfeeding education and support for nontraditional groups such as partners, grandparents and siblings. Concomitantly, the community doula training program continues to grow, starting as a regional training collaborative and growing into a statewide network of training, doula mentorship, and service provision for Medicaid families and families seeking community doula support.

The NJ TVP has served as a convener and collaborator to traditional health partners and non-traditional, community-based partners such as faith-based organizations. To address social determinants of health, the NJ TVP has taken a more expansive approach to identify and treat the issues most impacting the families in the state of New Jersey, with an acute focus on the populations that experience the worst health outcomes. These profound partnerships are essential in improving pregnancy outcomes, especially among marginal populations, addressing health disparities and structural racism, and reducing Black infant mortality. Utilizing innovative and evidence-based approaches to address cross-cutting issues that impact the health status of the most vulnerable populations is a critical piece of the developed and growing HWHF.

Additionally, NJ TVP partners with the NJ Maternal Health Innovation (MHI) Team at NJDOH and has implemented the Preterm Birth Prevention Program in NJ Communities. TVP engages with healthcare leaders at diverse organizations, for example, NJ sections of the American College of Obstetricians, the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), and the American College of Nurse-Midwives (ACNM); the NJ Perinatal Quality Collaborative (NJPQC); the NJ Health Care Quality Institute (NJHCQI); Federally Qualified Health Centers; hospital associations; regional New Jersey maternal child health consortia; foundations; and birthing hospital facility Chief Executive Officers, maternal health, and quality improvement experts.

Moreover, in response to the substance use crisis in NJ, TVP applied for and received in-depth technical assistance (IDTA) support from the National Center on Substance Abuse and Child Welfare (NCSACW) to develop a State Action Plan. In September 2022, NJ was selected by the NCSACW to participate in the 2023 Policy Academy: Advancing Collaborative Practice and Policy & Promoting Healthy Development and Family Recovery for Infants, Children, Parents, and Caregivers Affected by Prenatal Substance Exposure. The Policy Academy is supported by the Children's Bureau (CB), Administration on Children, Youth and Families (ACYF), SAMHSA, and HRSA.

This project, led by NJ TVP staff, includes a State Action Plan, developed collaboratively, to increase awareness of and capacity to address SUD during and after pregnancy for birthing individuals in NJ. The State Action Plan includes four overarching goals, all related to enhancing support for birthing people with SUD. The project aims to augment the screening, referral, and follow-up services pathways in the state substance use treatment systems of care. Ultimately, the goal of the IDTA group is to understand where resource gaps exist, creating a formal Plan of Safe Care to be distributed throughout the state and the crafting of a protocol for birthing hospitals and other providers to strategically support birthing people with SUD during and after a birth.

Colleagues in various state departments are working with the NCSACW to understand how pregnant women with SUDs are supported by various health providers and systems as they coordinate care throughout the state. The goal is in creating clinical systems of care that connect pregnant and parenting

people with SUD to appropriate levels of care throughout the state. In partnership with cross-system partners, the team led by TVP staff is composed of representatives from the Governor's Office (GOV), the Office of the First Lady, DCF, DHS, and the Department of Health (DOH).

# III.E.2.b. State MCH Capacity to Advance Effective Public Health Systems

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

Through the State Health Assessment, the State Health Improvement Plan, and the Department's Five-Year Strategic Plan, the NJDOH has identified the need to improve the public health workforce in the areas of access to care, quality improvement, systems integration, and population health management. MCH workforce development and capacity are also a priority for the Division of Family Health Services (FHS). Without an adequately trained MCH staff, vital Title V services and functions would not be provided to meet the needs of the current and future MCH population. Recognizing the value of experienced and trained staff, the FHS has taken action to improve the capacity of the MCH workforce despite the continued and negative economic repercussions related to the COVID-19 pandemic.

FHS implemented the development of succession planning to ensure essential functions were considered in long-term planning. During this past fiscal year, cross-training of staff was implemented to provide the ability to maintain key roles in the event of short-term staffing shortages. Changes in the workforce funded by Title V reflect NJ TVP's commitment to the MCH priorities and core functions.

Given the diversity of our state, cultural competency trainings continue to be provided to staff as an essential component of their continuing education activities. TVS also pursues other training opportunities through trainings offered at national conferences, including AMCHP, the MCH Epidemiology Conference, and the MCH Public Health Leadership Institute. Departmental trainings have been offered on ethics, grant writing, and grants management. Opportunities to supplement staffing through student internships, special temporary assignments, fellowship programs, and state assignees have also been successful. In 2023, FHS opened a collaborative opportunity with the Rutgers New Jersey Medical School to have medical school residents training for primary care on Maternal Health and Preventive Medicine to work with some of our Title V programs and staff. Thus far, FHS has had two residents who assisted in reviewing maternal health materials and documentation. The experience was mutually beneficial, and the collaboration will continue since primary care physicians who are also skilled in preventive medicine and public health is extremely important in advancing maternal health. The state of NJ remains focused on filling key positions and building the public health infrastructure in response to the state's expansive and diverse public health contexts. NJDOH was recently awarded a CDC grant (CDC-OE22-2203) which will create an Office of Workforce and Professional Development, with a main goal of holistically forecasting, planning, and assessing gaps in labor force, and determine ways to improve retention and invest in a talent pipeline that can complement the work being done in the TVP. The new Director of this office was selected from the MCH Unit, Division of Family Health Services and has more than 25 years' experience, starting in clinical work as a physician and transitioning into quality assurance in hospital system settings.

Most FHS staff recognized the need for incorporating the perspectives of families and family representatives into the MCH workforce under the broader umbrella of systems integration. Continued family involvement in health transformation is essential for effective program and policy development related to newly aligned systems. As a result, NJDOH collaborated with community partners through

advisory boards and steering committees to gain a better understanding of how family partnerships can complement and inform the work of the NJ TVP.

Maternal/Women's/Reproductive Health & Perinatal/Infant's Health

## MCH Workforce & Training

In 2023, Rebecca Ofrane, DrPH, joined the NJDOH as Executive Director of the Maternal and Child Health Services unit, reporting to the Title V Director. She brings a renewed focus on training and consistency to the unit. Other new staff who recently joined the MCH team to advance maternal and child health outcomes in NJ include the following. Gaëlle Casimir, Health Data Specialist Apprentice, will support the MCH Epidemiology team, including PRAMS data analysis. Ibiyemi Olawoye, Nurse Consultant, is a nurse and holds an MBA, and oversees the PPD-MD and FASD programs, as well as consults on other Reproductive and Perinatal Health Service programs. She brings community nursing and hospital experience to the team. Rebecca Shoaf Kozak, PhD, MSW is Manager of Special Projects. In this role, Rebecca works primarily on the Title V Block Grant annual application and five-year needs assessment and as a contributor to the state's Maternal Mortality Review Committee (MMRC). Rebecca brings experience as a clinical social worker and public health researcher to the team.

TVP continues to utilize the vulnerable populations plan created at the COVID-19 pandemic's peak, which guides the priorities of COVID-19 interventions such as exploring context in high needs areas such as areas where individuals are more susceptible to contracting COVID-19. The team has revised the plan to adapt it to the current needs of NJ residents. such as epidemiology expertise in high needs areas such as areas where individuals are more susceptible to contracting COVID-19. Additionally, the NJ COVID-19 vulnerable populations plan includes a list of populations deemed vulnerable to COVID-19, that includes racial and ethnic populations, immigrants, limited English proficiency, homebound, seniors, homeless, disabled populations, migrant workers, pregnant and nursing mothers, underinsured and uninsured, undocumented workers and substance abusers.

Many of these vulnerable populations face an increased risk of exposure to COVID-19 as many people experience lack of connection to clinical care, being uninsured or underinsured, difficulty in getting and maintaining a fair wage job and experiencing discrimination and bias based on the color of their skin or their socio-economic status. These populations are more likely to work in essential, low-income jobs that do not allow telework; and do not have health insurance or paid sick leave through employers. Racial and ethnic minority groups, seniors, people with low socioeconomic status, the homeless, those with SUD, pregnant women, and/or those with certain underlying medical conditions such as heart disease, diabetes, obesity, and smoking are also at increased risk of contracting COVID-19 and/or experiencing severe illness from COVID-19. Other populations such as immigrants, migrant workers, undocumented workers, limited English proficiency, and homebound and disabled populations traditionally do not access health care on a routine basis, thereby increasing their risk for severe disease. In addition, distrust of medical and governmental entities, anti-vaccination sentiments, and disparities in vaccine coverage may impact the achievement of high COVID-19 vaccination rates in these population groups. Knowing the value of CHWs along with their long-term use in NJ TVP programming, their limited training, lack of a standardized curriculum, and difficulty recruiting, retaining, and advancing in their careers, NJ TVP decided to invest, establish and build the NJDOH Colette Lamothe-Galette Community Health Worker Institute, https://www.nj.gov/health/fhs/clgi/.

Over the last several years, New Jersey has strategically invested in strengthening the infrastructure, knowledge base, and funding opportunities related to the expansion of the Community Health Worker

(CHW) workforce in the state. This coordinated response across the public and private sectors primarily related to the devastating health impacts of COVID-19 across many communities, particularly communities that historically have experienced significant health, social, and economic disparities. The CHW was identified to be an important component of a holistic solution, due to the role's proven success in not only engaging communities in care, but also in improving health equity and care outcomes.

In May 2020, NJDOH created the Colette Lamothe-Galette Community Health Worker Institute (CLG-CHWI), a program to train and certify CHWs. Training includes 144 hours of related classroom technical instruction covering 13 core competencies supplemented by 240 on-the-job hours, with reflective supervision as part of the training menu. Often, CHWs are frontline public health workers who are trusted by the people they serve because of their intimate understanding of the cultures, languages, and challenges of their neighborhoods. In addition to COVID-related support, CHWs provide unique support to pregnant and birthing people and their families, by helping connect women to Medicaid and prenatal care, identifying childcare and resources for preterm birth or children with special health care needs, and helping new parents identify postpartum care and available resources. NJ TVP has made the expansion of CHWs in NJ a strategy to address inequities in our healthcare system. One of the ways the NJ TVP has worked over the past several years to improve the health of vulnerable populations within the state is to support and help sustain initiatives that involve CHWs. This work has included efforts to establish standardized training, build CHW capacity, and expand the number of CHWs statewide.

Considering the SUD crisis in NJ, NJ TVP has been working on expanding CHW core competencies to include SUD training that offers specialized tracks related to primary actions of state and/or local public health-led efforts to address underlying causes of SUD. Moreover, additional training will be included to focus on the integration of CHWs in novel settings that include prisoner re-entry programs, mental health, and substance use disorders, Certified Community Behavioral Health Clinics (CCBHCs), and FQHCs; entities that have never utilized CHWs. These novel settings have been selected due to the challenges facing these vulnerable populations and the greater ease of accessibility to these vulnerable populations, and which is provided by these locations. This endeavor will be a part of innovative demonstration projects where we test the Return on Investment (ROI) of CHWs and explore sustainable funding strategies with Medicaid.

## Adolescent Health

Adolescents are best served by providers and professionals with an understanding of adolescent development and trending health issues. For those working with adolescents, like other special populations, level of skill and expertise matter. Therefore, CAHP is dedicated to assisting the NJ adolescent workforce in being prepared to address the complex needs of this age group. Education of the adolescent workforce is essential to the provision of high-quality health education and services for adolescents that are accessible, developmentally appropriate, effective, inclusive, and equitable. At all levels of professional education, providers in all disciplines serving adolescents need to be equipped to work effectively with this age group. They must be attuned to the nature of adolescents' health problems and have a range of effective strategies for risk assessment, disease prevention, care coordination, treatment, and health promotion in their clinical repertoire.

Currently, CAHP is staffed by four master's level professionals, one master's candidate, and an administrative assistant. Staff expertise consists of sexual health, counseling, public health, health science administration, education, and social work with a range of backgrounds, including direct service provision, program management, public school education, and community-based services. The Program

Manager has been with the Division, within the CAH Program for 8 years, all other staff have been hired over the past 3 years with the newest staff just completing their trainee year. Training is an essential part of CAHP. In addition to training in the EBMs implemented through programs, staff also received training in subject matter including but not limited to youth mental health, social and emotional learning, positive youth development and mentoring, and parent/caregiver engagement.

Current assessments of the adolescent workforce participating in NJDOH programs suggest the knowledge and skills of some providers/professionals working with adolescents lack essential skills and knowledge needed to serve this vulnerable population effectively. As an example, self-reported data on perceptions of professional competencies related to youth mental health collected via surveys of staff at twelve school districts prior to the implementation of Lifelines Trilogy suggested that members of the crisis team were unaware of or had misinterpretations of school policies regarding mental health. These limitations of staff included which tools to use for screenings, where to refer for services and when to include parents/caregivers. In addition, self-reported data from pre- and post-survey trainings provided to NJDOH grantees indicated a similar lack of knowledge and skills related to subjects such as birth control and other contraceptives, sexually transmitted infections, and social and emotional learning, prior to training. In our survey of adolescents, over 85% indicated they do not feel understood or supported by the adults in their lives (professionals, parents, and caregivers).

Given the current landscape of adolescent health education, support, and service needs, continued training and education of adolescent health professionals and providers is an important goal for the Child and Adolescent Health Program and the professionals/ providers who work with the adolescent population. To this end, NJDOH will be adding a professional engagement and training component to the Statewide Parent and Professional Engagement Program (S-PEP). Motivational Interviewing Training for Empowering Youth Toward Change will be free to youth serving professionals in NJ and will help assist providers in acquiring the skills needed to effectively serve children, youth, and young people in NJ.

#### Children with Special Health Care Needs

Within the SCHS unit, we have been focusing on workforce development in several ways. We envision what our organizational chart needs to look like in the future and build the positions to meet that expectation. Given that our unit includes surveillance, outreach, critical follow-up, case management, and grant management, we need a wide range of professional skills. Additionally, we have been focusing on bringing in early and mid-career staff. All staff are paired with more experienced staff, not only for training for job specific tasks, but also mentoring for professional growth. Providing and receiving mentoring are important tasks which enrich our staff.

As in medicine's "see one, do one, teach one" philosophy, we have started a grant group that exposes junior staff to the grant writing process, including having staff conduct "Grant 101" training, linking staff with mentors, and allowing staff to take the lead on grants with the more experienced staff acting as mentors and reviewers. Our philosophy is "see a few, work on some, write one." Additionally, we are bringing junior staff to board meetings, workgroups, and stakeholder meetings and letting them take on these roles over time. In the past year, we have received a HRSA PROPEL Grant to strengthen long-term follow-up for newborn blood-spot screening and a CDC Sickle Cell Grant for prevalence and education. Both were written by first-time "leads."

In terms of types of skills, we have been focusing on strengthening our nursing staff and our data staff. We were able to add two masters- prepared nurses to our unit. Both have extensive obstetrical bedside experience and will strengthen our birth defects registry activities. We will be adding another nurse

position within our Family Centered Care program this year, and this position will coordinate with county partners and well as provide clinical expertise for analysis of clinical acuity and use of case management services. Our data team continues to expand as our surveillance work with the CDC has expanded. Specifically, we are engaging with staff who abstract medical information, organize and enter data, and analyze and present data.

Data staff are embedded in the programs with content experts and clinical staff to allow for more collegiality, cross-training, and common learning among the data support staff, but also work collaboratively under one data system lead. While each program's data person is still the principal support for their program, other data staff were more familiar with their counterpart's data systems and could step in during staff shortages. By cross-training and having staff work on multiple data systems, they can ensure that we can meet our data demands even when staff is out, leaving, or retiring., The Coordinator started a monthly data group within SCHC, and then expanded to the division and other data staff across the department. Additionally, the SCHS unit has been able to leverage the cross-unit data ability and our SCHS programs to apply for and be awarded number federal grants.

In the last few years, FHS has encouraged cross program collaborations, and it began with the initiation of this monthly data group. Now led by a WIC colleague, these data group meetings are a forum for staff from MCH, WIC, EIS, and SCHS to learn about work being done across the Division that utilizes data systems of interest. It is a mechanism to expose staff to new ideas and information across the key programs.

Meeting the needs of emerging threats such as COVID, Zika, and natural disasters has often happened in an ad hoc manner. The focus has been on bringing in different types of staff who are able to write and execute funding opportunities, work with medical records, and organize and manage projects with quick turnaround times. Having the staff means we can be more strategic and timelier in collecting data and producing results and recommendations for changes.

Traditionally, we have only hired staff with nursing or social work degrees and experience with pediatric clients. These case managers work with families to provide resources and referral. In the past, we have also included Family Resource persons who were also parents or family members of a person with special health care needs. These staff were often limited in time and availability. We are moving to expand and be more flexible to include staff who have shared experience and who can offer families more community support. Community Health Workers who have received training for special health care needs will be one type of expanded staff that will be able to join our CMUs.

Additionally, we are planning to pilot test a regional case manager who will work with families with children under the age of six and who meet the criteria for autism and severe challenging behaviors. The project will partner with Autism New Jersey, one of our grantees, and provide more support, training, education, and guidance to families who need more intensive services. The goal will be to provide additional coping strategies, link families to more resources, and strengthen their resiliency.

## III.E.2.b.ii. Family Partnership

Maternal/Women's /Reproductive Health & Perinatal/Infant's Health

Building the capacity of women, children, and youth, including those with special health care needs and families, to partner in decision-making with Title V programs at the federal, state, and community level is a critical strategy in helping NJ to achieve its MCH outcomes. TVP has several initiatives to build and

strengthen family/consumer partnerships for all MCH populations, assure cultural and linguistic competence, and promote health equity in the work of NJ's Title V program.

Efforts to support Family/Consumer Partnerships, including family/consumer engagement, are in the following strategies and activities:

- Advisory Committees;
- Strategic and Program Planning;
- Quality Improvement;
- Workforce Development;
- Block Grant Development and Review;
- Materials Development; and
- Advocacy.

The public health issues affecting MCH outcomes disproportionately affect low-income and minority populations and are influenced by the physical, social, and economic environments in which people live. To address these complex health issues effectively, the TVP has incorporated consumer/family involvement in as many programs and activities as appropriate.

TVP prides itself on its regional MCH services and programs, which have been provided by the Maternal Child Health Consortia (consortia), located in the northern, central, and southern regions of the state. The consortia form a regionalized network of maternal and child health providers with an emphasis on prevention and community-based activities. Partially funded by TVP, the consortia are charged with developing regional perinatal and pediatric plans, total quality improvement systems, professional and consumer education, transport systems, data analysis, and infant follow-up programs. It is a requirement of the statute governing the consortia that 50% of their Board of Directors be comprised of consumers representing the diverse population groups being serviced by their organizations.

Recognizing the importance of parent/consumer involvement through focus groups in designing and implementing a program to address preterm births and infant mortality issues, the MCH Program incorporated focus groups into several programs under the HWHF initiative, including those for doulas, breastfeeding, and addressing disparities. The HWHF grantees have also established Community Advisory Boards with an emphasis on recruiting new and nontraditional partners. Similarly, the MIECHV also requires funded grantees to implement County Advisory Boards.

### Adolescent Health

Jennie Blakney, the Children, and Adolescent Health Program (CAHP) Program Manager, is the NJDOH representative on the NJ Youth Suicide Prevention Advisory Council, an advisory council to the Governor's office with membership from state departments, youth-serving professionals, and families. Most parents/caregivers that attend the committee have lost a child/teen/young adult to suicide. Their insight and input are essential to grant applications, services, and advocacy of youth/young adults struggling with suicidal ideation.

The CAHP currently implements Teen Speak, interactive training for parents and caregivers to help them improve communication with teens. Teen Speak offers a variety of educational and interactive options to help you find the format that works best for you. Pick one or try them all! Together the Teen Speak Series offers a comprehensive and supportive program for everyone supporting or parenting a teen. Teen Speak provides realistic scenarios and a detailed roadmap on how to tackle even the toughest conversations with

ease. CAHP's skilled facilitators, trained in Teen Speak deliver virtual and in-person learning sessions for parents and caregivers to help them enjoy the teen years, which can be challenging and exciting.

Children and Youth with Special Health Care Needs

The NJ Title V CYSHCN Program, SCHS, partners, collaborates, and coordinates with various governmental and non-governmental entities on federal, state, and local levels. Recently, the Governor's Office created an interagency workgroup of departmental programs which serve people with disabilities. The CYSHCN Director has sat on that committee since its inception. Dr. Howell provided an overview of our SCHS programs and an in-depth presentation of the New Jersey Autism Registry. These meetings have provided an excellent opportunity to build relationships and enhanced communication and collaboration. One strengthened relationship has been with the New Jersey Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. The Ombudsman Paul Aronsohn and his staff met with our FCCS team. Working together, the Ombudsman's Office can refer families with children to our case managers, and our CMUs were able to learn when and how to escalate cases to the Ombudsman's office. Recently, Dr. Howell discussed a new HRSA autism grant opportunity for long-term transition and was able to receive letters of support and a commitment to partner together if we receive this grant.

CMUs also work closely with parents, families and caregivers, primary care physicians, specialists, other health care providers, hospitals, advocacy organizations, and many others to facilitate access to coordinated, comprehensive, culturally competent care for CYSHCN. CMUs work with programs within the NJ DHS and DCF in addressing many needs facing CYSHCN, including medical, dental, developmental, rehabilitative, mental health, and social services. DHS administers Title XIX and Title XX services and provides critical support for ensuring access to early periodic screening detection and treatment for CYSHCN. The State DHS Medicaid, Children's Health Insurance Program Reauthorization Act NJ FamilyCare Program, and the Division of Disability Services afford eligible children comprehensive health insurance coverage to access primary, specialty, and home health care that CYSHCN and their families need. CMUs utilize patient satisfaction surveys to improve and refine their referral and linkage practice. Many trainings provided to grantees are also opened to parents/consumers as either participants or speakers. Educational materials and informational brochures for the CYSHCN population are reviewed by parents/consumers allowing for input for health literacy and cultural competence.

SCHS collaborates with many offices and programs in DHS to develop and implement policies that will ensure that children referred into the CMUs and their families are screened appropriately for healthcare service entitlements and waivered services. SCHS programs, including case management, specialized pediatrics, and Ryan White Part D, screen all referrals for insurance and potential eligibility for Medicaid programs, counsel referrals on how to access Medicaid, NJ FamilyCare, Advantage, and other applicable programs, and link families with their county-based Boards of Social Services and Medicaid Assistance Customer Care Centers. Program data, including insurance status, is collected into a report that is compared with Medicaid data in determining the needs for the CYSHCN referrals are made to Boards of Social Services, NJ Family Care, Charity Care, Department of Banking and Insurance, and Disability Rights NJ for support and advocacy. Recently, our CMUs have been working with Medicaid-eligible families to ensure that continuation of coverage.

Both the EHDI and the NSGS Programs within the SCHS also recognize the pivotal role that consumers and parents play in the effective administration of their programs. The EHDI Program includes parents

and consumers on the Hearing Evaluation Council, EHDI Advisory Committee and Quality Improvement Parent Group. Participants advise the NJDOH regarding meeting 1-3-6 guidelines and assist in the review of operations of the program. NSGS meets and communicates regularly with several advisory panels composed of parents of special needs children, physicians, specialists, and others to ensure NJ's program is state-of-the-art in terms of screening technologies, operations and responsive to any current concerns regarding newborn screening.

The Medical Assistance Advisory Committee (MAAC) operates pursuant to 42 CFR 446.10 of the Social Security Act. The 15-member committee comprises governmental, advocacy, and family representatives and is responsible for analyzing and developing medical care programs and coordination programs. State SCHS staff participate in MAAC meetings and share information on access to care through Medicaid-managed care with Committee members as well as with SCHS programs. Likewise, information shared by the MAAC is incorporated into SCHS program planning to ensure better coordination of resources, services, and supports for CYSHCN across systems. The quarterly MAAC meetings continue to provide a public forum for discussing systems changes in DHS's Medicaid program and invite collaboration across State programs. Updates keep stakeholders, including the public and providers, informed of NJ's progress in the implementation of Managed Long-Term Services and Supports, and the restructuring of services to children and youth with developmental disabilities through Division of Developmental Disabilities (DDD), DCF, DOE, and Division of Vocational Rehabilitation (DVRS).

SPAN and Autism NJ partner with SCHSCM for many initiatives and projects to better serve CYSHCN and empower families. The COCC, a leadership group of SPAN, dedicated to improving NJ's performance on the six core outcomes for CYSHCN and their families, includes three co-conveners from Title V, SPAN, and NJAAP. This group includes DHS, DCF, the NJ Primary Care Association, and over 60 participating stakeholder organizations statewide. The COCC partners are continuing to work to improve the access of children with mental health challenges to needed care and to improve the capacity of primary care providers to address mental health issues within their practice. A Family Guide to Integrating Mental Health and Pediatric Primary Care has been developed and shared with families. COCC co-conveners continue to meet with NJ's child protection agency, DCF Division of Child Protection and Permanency, about addressing challenges for children with mental health needs under their care. As an organization consisting of parents or families of CYSHCN, SPAN's guides, publications, and presentations are consistently developed, by design, with family and consumer involvement.

The New Jersey Early Intervention System (NJEIS) has a strong commitment to collaborating with families to ensure that early intervention services are aligned with their needs and preferences. NJEIS has four regional early intervention centers (REICs) that cover all counties across the state. Each REIC employs a Family Support Coordinator (FSC) who helps families navigate the system and actively participate in creating their child's Individualized Family Service Plans (IFSPs). This ensures that the services provided are individualized to address both the child's developmental needs and the family's concerns and priorities.

Furthermore, NJEIS actively engages parents in its governance and decision-making processes via the State Interagency Coordinating Council, which includes parents as members and is in the process of forming a parent committee. This involvement ensures that family perspectives are integral to shaping early intervention services, fostering an environment where parents feel their contributions are valued and impactful. NJEIS also routinely gathers family feedback through annual Family Outcome Surveys to continually refine and improve its services.

As evidenced by the multitude of advisory councils, consumer groups, coalitions, interdepartmental workgroups, and committees, the NJDOH greatly emphasizes the active and meaningful participation of parents and consumers in the development, design, implementation, and evaluation of Title V programs. This is a core strength of the NJDOH Title V programs.

## III.E.b.iii. MCH Data Capacity

### III.E.2.b.iii.a MCH Epidemiology Workforce

The MCH Epidemiology program is housed within the Maternal Child Health Services (MCHS) Unit of the NJDOH, FHS. Currently, it falls under the supervision of the Research Scientist I, who serves as the Project Director for the NJ Pregnancy Risk Assessment Monitoring System, and the State Systems Development Initiative (SSDI) and oversees all MCH Epidemiology activities. Presently the team encompasses a lead full-time MCH epidemiologist, two full-time Research Scientists II responsible for managing/analyzing MCH data and one Health Data Specialist Apprentice. Title V, MCH Block Grant, and the SSDI grant fund MCH Epidemiology positions.

The Research Scientist 1 in the MCH Epidemiology program serves as the Maternal and Child Health Epidemiologist Lead and the PRAMS Project Director. She integrates her clinical expertise with public health practice to focus on improving maternal and child health outcomes. Moreover, she designs and conducts complex statistical analyses to identify underlying factors associated with maternal and child morbidities at the state level. She has been instrumental in developing health data systems designed to improve maternal and child health outcomes in NJ. Her additional duties include designing and developing research protocols and conducting evaluation projects of maternal and child health initiatives implemented in NJ communities funded through the Title V grant. Moreover, she is responsible for preparing technical reports and needs assessments for programs; developing, reviewing, and analyzing publications and other documents pertaining to current MCH research developments; disseminating information to internal and external professional staff, and serving as the SSDI Project Director.

The Research Scientist II serves as the NJ PRAMS Coordinator. She has been the NJ PRAMS coordinator for the past nine years. Duties include: completing all SSDI required progress reports and continuation applications; responding to internal and external data requests; providing overall PRAMS project coordination; organizing PRAMS Steering Committee meetings; assuring compliance with the PRAMS protocol; completing all PRAMS progress reports and continuation applications. She plays a key role in coordinating PRAMS data dissemination and the development of PRAMS data briefs, topic reports, and the NJ State Health Assessment Data (NJSHAD) system PRAMS data query.

In May 2022, a second Research Scientist II joined the MCH Epi Team. Her role primarily involves expanding access to data across the state to improve mortality reviews and supporting data initiatives within the MCH Epidemiology unit. She promotes the health of pregnant women, infants, and children through the analysis of MCH data trends and facilitates efforts to develop strategies to improve MCH outcomes. Duties include: standardizing the methodological approach used by NJ Fetal Infant Mortality Review (FIMR) grantees, linking, and analyzing data, conducting applied research projects to provide information about improving health outcomes;, participating in the routine reporting of MCH indicators and birth outcomes research by demographic indicators, geography, and hospital; conducting data linkages and analysis for SSDI; and responding to internal and external data requests.

Most recently, in 2023, the MCH Epi unit onboarded a Health Data Specialist <u>Apprentice (HDSA)</u>. The HDSA has a Public Health background and is working towards her MPH with a concentration in

Epidemiology. The individual is getting trained in analyzing trends in MCH data, to facilitate efforts to develop strategies to improve MCH outcomes through data and applied research projects. The new team member supports all MCH Epi data-related projects. Duties include: linking and analyzing data and conducting applied research projects to provide information about improving health outcomes; linking PRAMS data to birth certificates and/or other data sources and conducting analysis, creating and updating PRAMS-related data for briefs and other reports annually; participating in the routine reporting of MCH indicators and birth outcomes research by demographic indicators, geography and hospital; conducting data linkages and analysis for SSDI; and responding to internal and external data requests.

To better identify the needs of the NJ MCH population, it is paramount for TVP to have access to quality data capable of informing MCH policies, need assessment activities, and program evaluation. Therefore, the MCH Epidemiology unit is working arduously to build and expand the NJ MCH data capacity to support TVP public health interventions and activities while contributing to data-driven decisions making in MCH interventions.

The MCH Epi unit has initiated several efforts to increase data capacity and advance the development and utilization of linked information systems between available datasets (WIC and Vital statistic data) to improve access to electronic MCH health data. Tile V Epidemiologists within the MCH unit use Statistical Analysis System (SAS) and LinkPlus software to perform deterministic and probabilistic data linkage. The data linkage projects are as follows:

Periodically, PRAMS Data is linked to NJ Birth Data, Universal Billing Data, and WIC Data, allowing for the development of statewide PRAMS queries posted on <a href="NJSHAD">NJSHAD</a> and updated yearly. Researchers and NJ TVS use the data query to track various programmatic activities, including infant sleep positioning and breastfeeding practices. This data query gives Title V staff more direct and timely access to NJ PRAMS indicators.

Epidemiologists within the MCH Epi unit periodically analyze the linked dataset and draft and post data briefs on the MCH Epidemiology webpage. The data presented in briefs derived from the Pregnancy Risk Assessment Monitoring System weighted survey responses.

Within the Maternal and Child Health Epidemiology unit, there has been a sustained effort and collaboration across MMRC, FIMR, and PRAMS teams. The NJ-FIMR program has worked with the NJMMRC to enhance its access to data sources and improve data standardization across its regional review teams. Findings from the annual PRAMS survey serves as a pertinent source of offering contextual information about the experiences of birthing people statewide as well as gaps in care identified by the FIMR and MMRC reviews. The NJMMRC, NJ-FIMR, and PRAMS staff, through their close collaboration on various data-related initiatives and projects, have significantly enhanced data connectivity across specific maternal and child health (MCH) data sources at the NJDOH.

#### Children with Special Child Health Services

Across the SCHS Unit, much of our work focuses on public surveillance of birth defects, autism, newborn screening disorders, and congenital hearing loss. Our teams work with federal partners such as the CDC to report on the prevalence of these disorders. Currently, there are five epidemiological/data staff employed by SCHS. Additionally, there are 1.5 FTE of contracted staff who work on specific grantfunded projects.

In the Birth Defects and Autism Registries, epidemiologic analyses have included sharing data on incidence/prevalence rates by county, maternal age, and race. Recently the epidemiology staff have been doing literature reviews to determine if the increasing use of GLP-1 agonists might be a concern for increased rates of birth defects.

Trends in Autism prevalence rate over the years and by children's race are examined, controlling for age of initial diagnosis. Risk factors including preterm birth, low birth weight, multiple birth and maternal age are analyzed and compared to other states in the Autism registry. This year, we will be adding another staff person who will be focusing on data analysis, reporting, and publication of the data. New Jersey has robust data set with over 53,000 children with autism in the registry. Additionally, Family Centered Care unit epidemiology staff have reviewed if there are diagnoses that are more or less likely to result in children being active in case management services. The newborn hearing screening program is analyzing various demographics, including race, ethnicity, maternal education and insurance status, on the rates of children receiving needed outpatient follow-up. The Newborn Screening and Genetics Services unit also conducted an analysis comparing screening data to state infant death files to determine if there were potentially undiagnosed cases of conditions screened for on the panel where infants were missed due to being just outside of the cut-off range for normal values. The prevalence of difference conditions over the years are presented in a Tableau dashboard.

## II.E.2.b.iii.b. State Systems Development Initiative (SSDI)

The Maternal and Child Health Epidemiology (MCH Epi) team promotes the health of pregnant women, infants, and children through the analysis of trends in maternal and child health data and facilitates efforts aimed at developing strategies to improve MCH outcomes through the provision of data and execution of applied research projects. Moreover, the MCH Epi program provides MCH surveillance and evaluation support to Maternal and Child Health Services.

Evaluating services for NJ mothers, infants, and children is important in improving access to health services and reducing disparities in health outcomes. The lack of comprehensive and timely data can limit the ability to make decisions supported by data. Reliance on official data that is sometimes three years old does not support an MCH system of care that is responsive to the changing needs of women and their families. The State Systems Development Initiative (SSDI) project, which resides in the MCH Epidemiology TVP, focuses on enhancing and expanding the NJ TVP data capacity by improving data exchange for linkages within the department and between other agencies. The NJ SSDI project is responsive to all NJ priorities. It focuses on integrating information systems that are deemed necessary to ensure the availability of timely information for decision-making in all priority areas.

The NJ SSDI project seeks to build, strengthen, and expand New Jersey's MCH data capacity to support Title V MCHBG program activities and contribute to data-driven decision-making in MCH programs, including assessment, planning, implementation, and evaluation. To ensure the continued effectiveness and readiness of data to inform Title V needs assessment, NJ SSDI staff within TVP established a robust data structure that includes data linkages using 'provisional' real-time data. By improving the MCH data structure, NJ is better able to support informed decision-making, provide effective and efficient resource allocation and improve the quality of programming for NJ's MCH population.

The NJ SSDI project plays a key role in advancing the development and utilization of linked information systems between key MCH datasets in the state. Data exchanges currently occur between MCH Epi, Vital Statistics, and PRAMS, also housed in the MCH Epi TVP and the Office of Population Health. Using birth data retrieved monthly and death data and hospital discharge data retrieved when the latest files are

available, the NJ SSDI project has expanded the use of recent provisional data for analysis, decision-making, resource allocation, and evaluation of NJ's MCH Title V activities. Partial funding of PRAMS is supported through the SSDI grant to ensure the availability of PRAMS data for linkage.

NJ TVP staff utilized the linked datasets to conduct analyses and produce reports (e.g., data briefs and topic reports). These reports are available on the MCH Epi webpage and the New Jersey Department of Health's State Health Assessment Data (NJSHAD) system. Thus far, TVP has demonstrated success in accessing and linking data across several data sources. The goals and objectives that the MCH Epi TVP will utilize the SSDI funds for the 2022-2027 SSDI grant period are depicted below.

- GOAL 1 Build and expand New Jersey's MCH data capacity to support Title V MCH Block Grant program activities and contribute to data-driven decision-making in MCH programs, including assessment, planning, implementation, and evaluation.
  - Objective 1.1 MCH Epi will provide data support to State Title V MCH Needs Assessment.
  - Objective 1.2 MCH Epi will improve linked birth and infant death certificates annually.
  - Objective 1.3 MCH Epi will link Perinatal files for the latest months available to provide current data for annual reporting and analysis.
- GOAL 2 Advance the development, access, and utilization of linked information systems between key MCH datasets in the state.
  - Objective 2.1 MCH Epi will implement the annual PRAMS survey, link data for Title V reporting, and other collaborative activities.
  - Objective 2.2 MCH Epi will obtain access to hospital discharge data annually.
  - Objective 2.3 MCH Epi will obtain National Immunization Survey data annually from their official website.
  - Objective 2.4 MCH Epi will advance the utilization of the minimum/core indicators data sets for Title V MCH programs.
- GOAL 3 Assist and provide program evaluation and data supports to inform New Jersey Department of Health's public interventions/ initiatives that align with the Nurture NJ Strategic Plan, which focuses on reducing maternal mortality and eliminating racial disparities in birth outcomes.
  - Objective 3.1 MCH Epi will design and conduct as-needed informative evaluation projects to inform the design and implementation of maternal and child health programs in NJ.
- GOAL 4- Improve data collection, analysis, and visualization to inform public health policies related to emerging issues.
  - Objective 4.1- MCH Epi will work on standardizing the NJ Fetal Infant Mortality Review (FIMR) case identification process.
  - Objective 4.2 MCH Epi will support FIMR committees in the process of uploading data to the National Fatality Review Case Reporting System (NFR-CRS)
  - Objective 4.3- MCH Epi will develop MCH Indicator reports for data visualization and utilization.

## III.E.2.b.iii.c. Other MCH Data Capacity Efforts

Maternal/Women's /Reproductive Health & Perinatal/Infant's Health

Title V data capacity efforts that are funded by sources other than SSDI include updating the annual MCH Block Grant performance measures, providing data for the Five-Year Needs Assessment, and providing customized data to internal and external partners for program planning and evaluation. In addition, the CDC provides funding to NJDOH to implement the NJ Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS is housed within the MCH Epi program and is a crucial surveillance tool necessary to improve the health of mothers and infants.

To inform program planning and evaluation, MCH Epi staff conduct PRAMS data analysis and develop PRAMS data briefs and topic reports. Additionally, the MCH Epi program, in collaboration with the Center for Health Statistics, developed a custom dataset query for NJ PRAMS data which is posted on the NJSHAD system on the NJDOH website. MCH Epi staff update the PRAMS data query annually.

Moreover, to increase the NJ data capacity, MCH Epi staff entered multiple other agreements not funded by the SSDI or Title V grants. The table below depicts 2 of MCH Epi's agreements in this grant cycle.

Agreement(s) an	nd Contract(s)			
Type of Agreement	Project(s)	Between		Description
Data Use	Fetal and Infant	NJ	Michigan	The purpose of this agreement is to
Agreement	Mortality Review	DOH	Public	establish the terms and conditions
		of Health-	Health	for the collection, storage, and use
		MCH Epi	Institute	of data obtained from the fatality
			(MPHI)	case reviews submitted by Fatality
				Review (FR) teams in the State of
				New Jersey and entrusted to the
				National Fatality Review Case
				Reporting System (NFR-CRS).

Data Use	Postpartum	Columbia	This agreement aims to enable
Agreement	Assessment of	University in	researchers at Columbia to use
	Health Survey	the City of	2020 NJ PRAMS survey data to
	(PAHS) study	New York	conduct the PAWS observational
	formerly known as		cross-sectional study and to return
	Postpartum		the link dataset to MCH Epi TVP for
	Assessment of		analysis.
	Women Study		
	(PAWS).		

Several CDC survey supplements have been included in the NJ PRAMS survey to collect data on emerging MCH issues. For example, in response to the COVID-19 pandemic, a COVID-19 supplement was added to NJ PRAMS in October 2020, a COVID-19 vaccine supplement was added in April 2021, and an Opioid Use supplement added in May 2024.

Another effort building data capacity in NJ is the development of a PRAMS for Dads/Partners survey, that the NJ TVP is leading in partnership with Northwestern University's Institute for Policy Research, who is coordinating PRAMS for Dads in 5 other states and with the CDC. Initiating a PRAMS for Dads/Partners survey will improve our understanding of and services for prenatal, birth and postpartum care and experiences, from the partners perspective.

Overall, the interoperability of data systems within the State is strengthening, with systems' interfunctionality and communication increasing in depth and scope. However, the teams working with the data of the state are acutely aware of data privacy issues as inter-system collaboration can provoke identifiability of data points due to small sample sizes of certain populations. The staff who manage the data systems continue to follow quality assurance protocols to limit issues of privacy.

## Adolescent Health

CAHP uses 3 separate databases/dashboards to collect program performance measures and program fidelity information for the PREP and SRAE Programs. In addition to these databases, the New Jersey Readiness to Stand challenge actively evaluates all aspects of program delivery. The NJ School Health (NJSH) recently released a competitive RFA which included the collection of program level outcome

data, NJSH will be determining how to best collect and disseminate data in the first year of the grant funding cycle.

Children and Youth with Special Health Care Needs

All Special Child Health Services programs work routinely with real-time files from the Vital Events Registration Information (VERI) system containing all birth and fetal death certificates. The NSGS Program data capacity is centered on the Revvity Laboratory Information System (LIMS), Specimen Gate, and Patient Care modules. This is a shared data system used by the Newborn Screening Laboratory and the Newborn Screening Follow-Up program. Additionally, the NSGS program has a Memorandum of Understanding with the Association of Public Health Laboratories, Inc. regarding the NewSTEPs data repository.

The Early Hearing Detection and Intervention program (EHDI) received inpatient hearing screening data via VERI, and outpatient hearing evaluations are reported in a module in the New Jersey Immunization Information System (NJIIS). Data from those sources are merged in an EHDI database and used to generate multiple reports to meet program needs. These include a monthly data reconciliation report and annual reports to hospitals, midwives, and audiologists.

The Birth Defects and Autism Registry System and the Case Management Referral System are developed and maintained via funding through a Memorandum of Agreement with Rutgers University. The CMRS system is undergoing a major overhaul to improve the system's ability to be flexible in responding to new situations, such as future pandemics and natural disasters that will impact the service needs of children with Special Health Care needs. Furthermore, the system redesign helps improve the quality of data reporting, improve the user experience, and implement an acuity measurement. The acuity measurement will be developed through a weighted scale that utilizes pivotal information from CMRS, such as diagnosis, linkage to services, insurance information, medical home, transition to adulthood, and other key data to determine each child's level of acuity in a format that is easily understood and utilized by stakeholders. These data elements allow Family Centered Care Services (FCCS) staff to evaluate staffing of Case Management Units at County level to respond to communities of greater need and determine each child's real-time level of need at-a-glance.

As part of a cooperative agreement, SCHS programs provide de-identified hearing screening, follow-up data on all NJ occurrent births, case data for certain congenital disabilities, critical congenital heart defect screening results, and both maternal and newborn data, including infant outcomes up to six months of age for cases with pregnancy complicated by COVID-19 infection.

SCHS is working with New Jersey Innovation Institute (NJII) staff, a New Jersey Institute of Technology corporation, on a Master-Person Index (MPI) project. NJII has worked with other DOH programs to use data algorithms to establish a MPI to link individuals across data systems. NJII is receiving hospital admission data and VERI and NJIIS records to create MPIs for millions of individuals. SCHS has created a charter to put the BDARS records through a process to assign MPIs to the BDARS records to facilitate matching data with birth certificates and other data systems. The program has completed the initial BDARS data match and is exploring assigning MPI to other SCHS data systems, such as the NSGS program data.

Another effort to improve data capacity and quality is the recent implementation of batch-processing upload option for BDARS records. Initially, the program uses this process to create BDARS records for children with confirmed disorders identified by the NSGS program. This functionality will later be rolled

out to hospitals to allow them to create data files to be uploaded with new cases, to replace having staff manually complete the BDARS form for each new case.

## **III.E.2.b.iv. MCH Emergency Planning and Preparedness**

In January 2023, the New Jersey Department of Health (NJDOH) released the Continuity of Operations Plan (COOP) that will be reviewed and updated annually. This COOP plan presents a framework that establishes the operational processes/procedures to sustain essential functions when normal operations are not feasible and provides the necessary guidance for restoring the Department's full functions following a disruptive event. This plan was adapted from the U.S. Department of Homeland Security, Homeland Security Preparedness Technical Assistance Program's COOP Sample Plan Template document.

In collaboration with other DOH leaders, the Assistant Commissioner of Family Health Services, who also serves as the Title V Director, participated in developing the COOP. Moreover, all divisions, including the Division of Family Health Services, where Title V primarily resides, are part of the COOP's development and maintenance. Title V leadership is involved in developing and implementing the COOP and is also part of the Rapid Mobile Response Team (RMRT) that the Division of Emergency Preparedness leads.

This COOP plan enables the Department to identify the essential functions that need to be preserved and to develop the requisite strategies that may be required to maintain these essential functions in the event of any disaster or emergency that could potentially disrupt governmental operations and services. The team developed a COOP decision process. The table below depicts the different levels of emergency and the potential impact on the agency.

Class / Level of Emergency	Impact on Agency
I	Disruption of up to 12 hours, with little effect on services or impact to essential functions or critical systems.
	No COOP activation required, depending on individual agency
	requirements.
II	Disruption of 12 to 72 hours, with minor impact on essential functions.
	Limited COOP activation, depending on individual agency requirements.
III	Disruption to one or two essential functions or to a vital system for no more than three days.
	May require movement of some personnel and equipment to an
	alternate facility/work site or location in the primary facility for less than a week.
IV	Disruption to one or two essential functions or to the entire agency with potential of lasting for more than three days but less than fourteen days.
	May require activation of orders of succession for some key personnel.

Historically, the NJDOH has prepared for emergencies by looking outward to the communities it protects. The NJDOH also partners with public health partners who will assist in implementing emergency operations efforts when needed. Through these efforts, DOH has become increasingly aware of the extent to which disasters and emergencies can weaken and damage our capabilities to deliver essential governmental and programmatic functions and services to the people and public health partners.

All programs in DOH addressed emergency preparedness in various ways. The Family-Centered Care Program in Special Child Health is upgrading the current case management reporting system to enable the program to quickly reach out to all families with children with special health care needs receiving case management services. This system includes an "exceptional events" module that has been redesigned to allow more flexibility in collecting the family's needs and how they can be utilized and better serve the community during emergencies. Additionally, case management units utilize email, phone calls, text messaging, and letters for direct communication and emergency situations. To expedite communication with families, the upgraded system will include a SMS text messaging capability and email functionality. This will allow case management units to efficiently communicate with families regarding their individual needs and distribute mass communications in real time swiftly in case of an emergency event.

The Newborn Screening and Genetic Services, Follow-Up program, has plans for how to continue operations when staff is not able to report to a given worksite, when the Laboratory Information Management System (LIMS) is not available, and for when the DOH network is down. These plans are coordinated with the NJ Newborn Screening Laboratory. The New Jersey Public Health and Environmental Laboratories (NJPHEL), Newborn Screening Laboratory, has a laboratory coverage agreement for backup services to ensure continuity of operations.

The COVID Pandemic highlighted key gaps in data and surveillance that were quickly rectified with an emergency response dashboard that highlighted COVID positive rates and vaccination rates among NJ residents. Since this, the NJDOH has been committed to continuing surveillance and data management by creating a centralized data hub and a maternal data center that specifically focuses on NJ families' health indicators.

Pregnant women, infants, and children have unique risks with public health emergencies. Gaps in emergency preparedness and response planning can leave MCH populations especially vulnerable. For instance, the COVID-19 pandemic necessitated an immediate response to address the needs of MCH populations. Services and resources were quickly transitioned into remote access when possible. TVP grantees continue to offer a hybrid option to the population being served by our programs.

Published studies confirm the pre-pandemic persistent racial/ethnic health disparities and their exacerbation during the COVID-19 pandemic. These results illuminated the deep racial inequities and gaps in the US public health and healthcare systems. Per the literature, the discontinuation and/or scaling back of lifeline services during the pandemic is believed to have exacerbated preexisting socioeconomic and emotional challenges. Some of the key lessons that TVP learned through the pandemic is the need to be flexible on how resources and services are delivered to the MCH population in NJ. For example, many healthy centers transitioned to offering telehealth/telemedicine during the pandemic to accommodate patients and be compliant with CDC and hospital guidelines. Additionally, during the COVID-19 pandemic's peak, NJ WIC agencies allowed for certification of WIC participants remotely, making it easier for eligible applicants to receive WIC benefits. Additionally, during the recent infant formula shortages, WIC shoppers were provided the option to purchase a wider variety and sizes of WIC foods,

including contracted (Mead Johnson, maker of Enfamil) infant formula products. The team also updated the WIC WOW MIS system WIC Shopper app, UPC codes, and grocery systems to make them more accessible to clients and easier to use.

# III.E.2.b.v. Health Care Delivery System

### III.E.2.b.v.a. Public and Private Partnerships

The NJDOH collaborates with many other federal, state, and non-governmental partners to complement Title V program efforts to provide a systems approach to ensure access to quality care and needed services for the MCH population. Through the First Lady's Nurture NJ, a statewide awareness campaign committed to reducing maternal and infant mortality and ensuring equitable care among women and children of all races and ethnicities, the NJDOH has partnered with other state departments and agencies, including health systems, physicians and midwives, doulas, community organizations, and most importantly, mothers and their families to make a transformational change in a system that has historically failed mothers and babies.

The Nurture NJ Strategic Plan was released in January 2021. It requires all sectors, including health and Title V, as well as education, housing, business, government, justice, and others, to join forces. This Strategic Plan was developed to reduce NJ's maternal mortality by 50% over five years and eliminate racial disparities in birth outcomes. This plan culminated over a year of in-person and virtual meetings with over 100 critical stakeholders, including national public health experts, NJ state departments and agencies, health systems, physicians, doulas, community organizations, and mothers and families. The plan seeks to reduce maternal mortality and eliminate racial disparities by ensuring all women are healthy and have access to care before pregnancy. In addition, the plan includes the strengthening of a safe, high-quality, equitable system of care for all women prenatally through postpartum care and a plan to ensure supportive community environments are cultivated during every other part of a woman's life so that conditions and opportunities for health are always available. Nurture NJ partners continue to work together to implement the recommendations.

In June 2021, NJDOH launched the NJMCQC, a 34-member of legislated State Maternal Health Task Force. Assistant Commissioner Nancy Scotto-Rosato, also the Title V Director, engages in multiple MCQC-related activities and supervises the Team that conducts MCQC-related activities within FHS. The NJ MCQC is part of the HRSA-funded SMHIP, a selective innovation program to complement ongoing Title V programs nationwide. The NJMCQC coordinates efforts and strategies to reduce maternal mortality, morbidity, and racial and ethnic disparities within the state. The NJMCQC works collaboratively with TVP and other organizations, such as the Perinatal Quality Collaborative, involved in developing and implementing maternal mortality and morbidity reduction strategies within the state. The NJMCQC convenes quarterly to promote buy-in, implement the Nurture NJ Strategic Plan, translate data into action, strategize on future activities, and solicit funding opportunities. The vision to make NJ the safest and most equitable place in the nation to give birth and raise a baby is at the forefront of the work of the NJMCQC and is supported by TVP.

Moreover, in FY23, in partnership with the Governor's Office (GOV), the Office of the First Lady, DCF, DHS, and lead by DOH developed a State Action Plan to promote healthy development and family recovery for infants, children, parents, and caregivers affected by prenatal substance exposure. In FY24, the Team will start implementing the Action Plan. The appointed Team Leads across each department are

well-versed in coordination and community capacity building. Moreover, they have solid partnerships with key stakeholders and state leaders to enact the State Action Plan successfully.

Lastly, private foundations work collaboratively with NJDOH and TVP to complement and coordinate funding priorities. For example, the NJ Birth Equity Funders Alliance, a coalition of private funders, contributes funding towards community doula efforts through the NJ Doula Learning Collaborative and the NJ Health Care Quality Institute, to develop model hospital policies related to doula access.

# III.E.2.c State Action Plan Narrative by Domain

The Life Course Framework/Perspective offers an integrative approach to understanding person-inenvironment, and the multitude of ways our health is impacted over the trajectory of life. The Life Course Perspective challenges assumptions of the root causes of health outcomes in the State's populations; especially, populations on the margins. The NJDOH advances the development of programs aimed at pinnacle developmental phases to reduce disparities and improve outcomes for children, youth, and families in our State.

The NJDOH believes that meaningful and equitable health reforms are borne out of programs and policies that endorse a Health Equity approach to the work. A Health Equity Lens works in tandem with the Life Course Perspective insofar that both frameworks mandate an orientation toward high quality, informed programming that scrutinizes the micro, mezzo and macro level systems in which individuals and communities thrive. It is through these critical lenses that the endeavors listed here are created and realized.

## Women/Maternal Health- Annual Report

Improving the domain of Women's/Maternal Health is crucial to the State Priority Need of Increasing Equity in Healthy Births (SPN #1) and the National Outcomes Measures (NOMs) 2, 3, 4, 5, 6, 8,9.1, 9.2, 9.3, 9.4, 10, 11,23 and 24. The selection of NPM #1 (Well Women Visits) during the Five-Year Needs Assessment process recognizes the impact the life course approach will have on increasing healthy births and improving women's health across their life span. The Life Course Perspective to conceptualizing health care needs and services evolved from research documenting the impact of life events on the developing psyche, from birth through adulthood, and how the cumulative experience of these events contributes to the ultimate shaping of an individual's health trajectory. The interplay of risk and protective factors, such as socioeconomic status, toxic environmental exposures, health behaviors, stress, and nutrition, influence health throughout one's lifetime. NJ has prioritized improving women's health and has utilized several evidence-based strategies to increase preventive medical visits (NPM #1) including the HWHF, MIECHV, FIMR, and Maternal Mortality Review. The Murphy Administration has placed additional emphasis on reducing maternal mortality and morbidity through the Nurture NJ Initiative.

3.e.2.c.2.a - Annual Report - NPM #1 (Percent of women with a past year preventive medical visit)

Table NPM # 1										
	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Percent of women with a past year preventive medical visit (all)	77.7	77.3	78.8	79.8	80.5	77.0	82.4	**	78.7	78.0

Data Source: <u>Behavioral Risk Factor Surveillance System (BRFSS) in NJSHAD.</u> Visited a Doctor for a Routine Checkup in the past year (Age-adjusted).

\*\* Data not available

Evidence-Based Informed Strategy Measure (ESM) 1.1 (Increase First Trimester Prenatal Care) was selected for its positive impact on National Performance Measure (NPM) #1 (Well Women Care) and State Performance Measure (SPM) #1 (Increasing Healthy Births).

In 2021, the overall percentage of adequate prenatal care based on the Kotelchuck Prenatal Care was 71.2%. However, racial/ethnic disparities are observed. Specific race/ethnicity-related rates for adequate prenatal care for 2021 were 77.6%, 60.7%, and 64.6% for White NH, Black NH, and Hispanic individuals, respectively. These existing disparities align with the need for TVP to improve NPM #1 by focusing on preconception care and early prenatal care. Improving access to prenatal care is essential to promoting the health of NJ mothers, infants, and families. Early and adequate prenatal care is an important component of a healthy pregnancy and birth outcome because it offers the best opportunity for risk assessment, health education, and the management of pregnancy-related complications and conditions. Prenatal care is also an opportunity to establish contacts with the health care system and to provide general preventive visits.

Moreover, preconception care is a critical component of prenatal and health care for all women of reproductive age. NJ has a targeted focus on preconception care through the family planning program. The NJ family planning grant delivers essential primary and preventative health care to patients. NJ's family planning providers provide a full range of reproductive health and family planning services, including contraceptive counseling and provision; education, testing, and treatment for sexually transmitted infections; screenings for breast and cervical cancers; and other sex education. In the fiscal year 2023, additional funding was appropriated for abortion services and support to cover uncompensated costs, practical support, and a statewide needs assessment.

The main goal of preconception care is to provide health promotion, screening, and interventions for women of reproductive age to reduce risk factors that might affect future pregnancies. Given the relationship between pregnancy intention and early initiation of prenatal care, assisting women in having a healthy and planned pregnancy can reduce the incidence of late prenatal care and promote NPM #1 (Well Women Visits).

Through the HWHF initiative, TVP uses CHWs, postpartum doulas, and partners with Connecting NJ to focus on improving maternal and infant health outcomes, including women's health with preventive medical visits, preconception care, prenatal care, inter- conception care, preterm birth, low birth weight, and infant mortality. The primary focus of Connecting NJ is to assist pregnant people, caregivers (mothers, fathers, grandparents, kinship, foster parents, legal guardians), and young children (birth to five) in efficiently accessing the most appropriate services, with more than 80% of referrals made for pregnant women. On the Connecting NJ portal, reported data include but are not limited to health status, diagnosis, socio-demographic characteristics, and more.

TVP staff have access to data collected on this secure system. Connecting NJ is designed to simplify the referral process, improve care coordination, provide developmental screening, and ensure an integrated maternal, infant, and early childhood care system. From July 1, 2018, to March 1, 2024, more than 111,420 pregnant individuals have been screened and there have been over 79,860 service referrals offered to these individuals. To better align the ESM with our current initiatives, ESM 1.2 (Number of individuals trained to become community-based doulas) was selected for its positive impact on National

Performance Measure (NPM) #1 (Well Women Care) and State Performance Measure (SPM) #1 (Increasing Healthy Births).

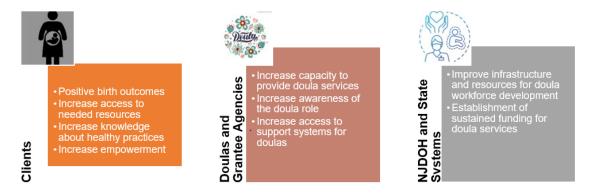
In 2021, an RFA was issued to create a NJ Doula Learning Collaborative, which was awarded to Health Connect One. The Doula Learning Collaborative (DLC) focuses on reducing maternal and infant mortality and eliminating racial disparities in health outcomes by providing training, workforce development, supervision support, mentoring, technical assistance, direct billing, and sustainability planning to grow the community doula workforce.

To date, almost 300 individuals have been trained to become community doulas, and as of April 2024, 767 births have been supported by NJ's trained community doulas. Preliminary results from an evaluation conducted by researchers from Montclair State University in 2021 for the 3-year Doula Pilot Program indicate that positive birth and/or pregnancy outcomes (e.g., lower rate of cesarean deliveries, increase in breastfeeding rate) are linked to community doula services.

A mixed-methods outcome evaluation was conducted to examine the outcomes and benefits of the Doula Pilot Program as measured by quantitative data (i.e., program data from the Maternity Neighborhood database) and qualitative data (i.e., interviews with program stakeholders). Program outcomes and benefits were observed at three stakeholder levels: 1) client, 2) doula and grantee agency, and 3) NJDOH and state system levels (Figure 15).

Several actionable recommendations have emerged from the evaluation project on how to improve the implementation and outcomes of ongoing efforts related to the Doula Pilot Program. Overarching recommendations are provided, and specific actions that multiple stakeholder groups may take are offered to provide targeted guidelines for program improvement. The recommendations emphasize collaboration across stakeholder groups and are mutually reinforcing. To ensure the sustainability of community doula services in NJ, TV staff worked collaboratively with Medicaid to offer community doula services to women through NJ FamilyCare benefits. NJ FamilyCare Medicaid benefits have been expanded to cover community doula services. Presently, a doula can serve birthing people whom NJ FamilyCare covers as a covered benefit. In addition, NJDOH's TVP works collaboratively with private funders in the state, including the Burke Foundation, to offer complementary doula training and apprenticeship programs.

Figure 15. Program Outcomes Across Clients, Doula and Grantees Agencies, NJDOH, and State Systems



Moreover, TVP established the Collette Lamothe Galette-Community Health Worker Institute (CLG-CHWI) through a NJ Department of Labor Apprenticeship program to infuse additional services in the communities. TVP collaborates with community colleges throughout the state to create a standardized community health worker training and certification program, resulting in a robust CHW workforce. This

apprenticeship opportunity has allowed the state to educate an emerging and critical component of its workforce – creating a needed infrastructure to support CHWs, enhance CHW skill sets, and lead sustainable efforts to support this indispensable workforce. Graduation of the initial cohorts has already begun, with new cohorts continuously being enrolled, with over 600 CHWS trained through the CLG-CHWI thus far.

Moreover, CHWs and their supervisors, through Title V grantees, have received and continue to receive breastfeeding education. This unique training focused on women of color and was developed to address health disparities related to reproductive justice. Breastfeeding support is also being provided by International Board-Certified Lactation Consultants (IBCLC) either in groups or in one-to-one sessions.

The programs being implemented in the communities through the HWHF initiative allow TVP to implement specific activities to support communities with limited public health resources. Additionally, the programs focus on the highest need where impacts will be greatest to improve population health outcomes and reduce health disparities. The HWHF Initiative addresses the disparities in birth outcomes through case management and assures that appropriate referrals are made and tracked including medical care referrals to promote NPM #1 (Well Women Visits).

To ensure that the HWHF initiative is successful, NJ TVP collaborates with the NJDOH Office of Population Health and the Population Health in Action Teams. Through this collaboration, TVP established linkages with sister agencies (Department of Labor, Department of Education, Department of Transportation, etc.) and sought to address some of the barriers that exist in the scope of social determinants of health. Additionally, efforts to reduce maternal mortality and morbidity have been and continue to be developed under First Lady Tammy Murphy's Nurture NJ Initiative, whose goal is to "make NJ the safest place to give birth in the country."

### **Annual Report - NPM #14:**

Percent of women who smoke during pregnancy and Percent of children who live in households where someone smokes.

The adverse effects of parental smoking and vaping on children have been a clinical and public health concern for decades, first formally documented in the 1986 U.S. Surgeon General's Report and ever since in public health and medical scholarship. Unfortunately, millions (more than 60%) of children are exposed to secondhand smoke in their homes. These children have an increased frequency of related hospital admissions during infancy; severe asthma and asthma-related problems; lower respiratory tract infections leading to 7,500 to 15,000 hospitalizations annually in children under 18 months; and sudden Unintended infant death (SUID). As a result of the many health consequences, the health costs of smoking during pregnancy are significant. Excess prenatal care costs and complicated births among pregnant women who smoke exceed \$4 billion a year. (See NJ Pregnancy smoking rates in table below). It has been estimated that a 1% drop-in rate of smoking among pregnant women could result in savings to the US of \$21 million in direct medical costs in the first year. Another \$572 million in direct costs could be saved if the rates continued to drop by 1% annually over seven years. Secondhand smoke also has significant health effects on an infant.

Pregnant women exposed to secondhand smoke have a 20% increased risk of delivering an infant of low birth weight, and secondhand smoke exposure also increases the risk of infections in the infant possibility of death from SUID. Children living with smokers/vapers are also more likely to have more frequent and acute asthma attacks, ear infections, and serious respiratory illnesses like pneumonia and bronchitis due to

second and third-hand smoke exposure (See NJ exposure in Table B below). The cost to care for childhood illnesses resulting from exposure to second and third-hand smoke is estimated at \$8 billion annually. In addition to the effects during the perinatal period, health consequences for older children and adults (whether from direct smoking or second /third-hand exposure) are well documented in the literature and include respiratory infections, cancer, and death.

### Perinatal Risk Assessment Data

\*Majority of assessments completed by Medicaid recipients and not representative of the state overall

Year	Smoking in the month before you knew you were pregnant (4Ps Q8)	Pregnant Woman 2nd or 3rd Hand Smoke Exposure (PsychSoc Q)
2017	8.8%	7.3%
2018	7.8%	5.6%
2019	7.7%	6.0%
2020	6.0%	3.4%
2021	4.7%	2.1%
2022	4.1%	2.2%
2023	4.5%	2.1%

Initiated in 2001 with funding from the NJDOH-Comprehensive Tobacco Control Program, Mom's Quit Connection (MQC) is NJ's maternal child health smoking cessation and education program. Changes have occurred in service provision as the capacity of the statewide program has been based on availability of funds. MQC utilizes a proactive behavior modification model, offering face-to-face individual cessation counseling, telephone counseling, and texting support to assist clients in developing a customized quit plan. Through these direct services, both for consumers and professionals, MQC focuses on reaching the women and family members who need help to quit. They educate them about tobacco use's dangers and offer judgment-free, evidenced-based treatment methods by Nationally Certified Tobacco Treatment Practitioners and NJ Certified Tobacco Treatment Specialists.

The program was expanded during FY 2015 and Mom's Quit Connection (MQC) developed a multipronged and comprehensive statewide approach to perinatal smoking cessation activities.

#### The new activities include:

- Promoting Mom's Quit Connection (MQC) to further expand its reach to pregnant and parenting individuals in NJ.
- Increasing Mom's Quit Connection's capacity with direct services for pregnant and parenting individuals statewide.
- Preventing relapse after delivery.

## Additional Goals and Objectives of the program:

By June 30, 2024, train 150 clinicians to utilize the AAR Brief Intervention Model to identify tobacco users and refer birthing people, parents, and family members to MQCF/Quit for Kids and achieve a minimum 80% average confidence in utilizing the AAR model at the post training survey.

By June 30, 2024, provide education and encourage smokers to enroll in MQCF. This can include in person events, as well as print, digital, and social media education distribution about the dangers of tobacco exposure during pregnancy and the risk of second and third hand smoke or vapor exposure for infants and children.

In January 2018, the MQC database software program was redesigned and upgraded to a web-based system using the Salesforce platform to support more detailed reporting and integration of planned mobile technology. Given the declining rate of maternal smoking and the stagnant and, in some cases increasing numbers of postpartum women returning to smoking after delivery, MQC chose to rebrand to MQC for Families. According to PRAMS Briefs published by the NJDOH, living with other smokers represented the most prevalent indicator for postpartum relapse. Expanding the program to MQC for Families has enhanced its cessation population parameters to include parents and caregivers of children under 8 years old along with the pregnant woman to address not only the individual smoker but all smokers in the home environment. Helping clients quit smoking and vaping is a harm reductive effort that positively impacts all in the home. Multi-level interventions are standard, including mailing self-help materials, phone calls, texting, and direct individual cessation services. Relapse prevention interventions are an important part of the program to address the high relapse rates post-partum.

MQCF staff offer Orientations about the MQCF and the Quit for Kids programs to providers. These Orientations discuss program parameters, referral options and the cessation resources available, to help attendees successfully implement these programs as a resource for Smoking Cessation services in their organizations. Almost 1,200 professionals have been served this year to date (July 2023 – Jan 2024).

MQCF's presence on social media remains strong. A total of 574 users visited the MQCF website, with 451 of them unique/new users. The website continues to be a source of referral to the program, with 9 online self and provider referrals this quarter. Through the connection with FindHelp.org, 13 individuals received information on MQCF services and through its website. Every effort is being made to continue social media outputs, which is the least expensive media venue. MQCF information and website are also now included on the Tobacco Free for a Healthy New Jersey (TFHNJ) monthly infographic. Viewers can click on the MQCF/QFK information, and the link will take them to the website. MQCF program information and tobacco use during pregnancy information are also included on the Prematurity Prevention Initiative (PPI) website and Facebook pages. Staff work closely with PPI staff to post information as well as referral options to MQCF. There was a total of 349 users to the PPI website, with 247 new users. 560 pages were viewed on the PPI website. The PPI Facebook page had a post reach of 433.

MQCF staff discuss the tobacco resources available on the SNJPC Resource Webpage, and best ways to monitor and update the listings. This site provides an order form to select tobacco resources, and these are then mailed to the provider. The site was updated to include a revised flyer in both English and Spanish of MQCF programs which provides a QR code to the MQCF website, as well as a smoking and diabetes MQCF brochure. From July 2023 to January 2024, MQCF had 1,549 completed client contacts, including phone, text or in-person session, counseling introductions, intakes, and providing materials. MQCF continues to offer Client Education through Zoom and In-person by request. So far this year, MQCF staff conducted 12 Formal Client Education programs with 175 participants and 9 Informal Client Education

programs with 296 participants. MQCF attended 22 Health Fair/Community Partner Events with 622 participants.

## Tables NPM 14A & B:

Percent of women who smoke during pregnancy (last 3 months)

	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
14A. Percent of women who smoked during pregnancy	5.7	5.5	5.6	4.8	4.4	4.4	3.5	3.1	2.9	2.7	2.2	1.4

Notes - Data is from the NJ PRAMS Survey

Percent of children who live in households where someone smokes:

	2007	2011-2012	2016	2017	2018-2019	2020-2021	2022
14B. Percent of children who live in households where someone smokes	19.7	20.3	n/a	n/a	9.7	9.7	7.5

Data Source: National Survey of Children's Health (NSCH)

## Women/Maternal Health – Application Year

Plans for the coming year to promote NPM 1 (Well Women Care) will include the continuation of HWHF and collaboration with families, partners, and stakeholders in the newly implemented State Maternal Health Innovation Program. The goal of HWHF continues to be to improve maternal and infant health outcomes for women of childbearing age (as defined by CDC as 15-44 years of age) and their families, especially Black NH and Hispanic women, through a collaborative and coordinated community-driven approach. The HWHF Initiative will continue to develop partnerships with community-based maternal and child health providers/agencies with proven capabilities in implementing activities/interventions within a targeted community. Furthermore, the program will have the capability to focus on reproductive-age women and their families.

The relaunch of HWHF focuses on implementing breastfeeding education and postpartum support. Support programs for breastfeeding include 1:1 and group sessions by IBCLCs and peer counselors, the establishment of culturally and linguistically appropriate support groups. In addition, new breastfeeding educational sessions targeted to non-traditional groups such as fathers, support persons, teenagers, and grandparents have begun. To support the continued increase in breastfeeding initiation at birth, a statewide Breastfeeding Strategic plan was launched in 2022 and is currently being implemented, with the assistance of a recently hired Statewide Breastfeeding Coordinator.

Simultaneously, county-based consumer-driven advisory boards will continue to contribute to the direction and progress of the HWHF initiative, and the Connecting NJ Hubs will meet quarterly to build partnerships and local referral systems. The MIECHV Programs and Healthy Start Programs will continue to case manage mothers and assure preventive medical visits through the monitoring of benchmarks, including a reproductive life plan, medical home, and well-women visits. MIECHV is one program among a growing state network of home visiting, including NJ's newly launched universal home visiting program. This program, NJ Family Connects, is coordinated by DCF, and collaborates with MIECHV and our other TVP MCH programs such as ConnectingNJ and community doulas.

The Doula Learning Collaborative will continue to provide training, workforce development, mentoring, technical assistance, direct billing, and sustainability planning to community doulas and doula organizations throughout the State of NJ. To date, almost 300 individuals were trained to become community doulas, and as of April 2024, over 750 births were supported. In conjunction with NJDOH, the Doula Learning Collaborative created a comprehensive, unique training curriculum for NJ community doulas. It provides cultural competency training and education in NJ-specific community-based resources for doulas. It is working with Medicaid to ensure that the NJ community doula training curriculum is approved for community doulas to enroll as NJ FamilyCare Community Doula provider to receive Medicaid reimbursement.

The Collette Lamothe Galette – Community Health Worker Institute (CLG-CHWI) will continue to enhance the professional development of CHWs and allow for a stronger workforce. Over 600 CHWs have completed their training. The CLG-CHWI will continue to expand its programs through state funding and now will include apprenticeships for perinatal CHWs, an initiative to improve maternal-child health outcomes, Peer Mentors, and Certified Nurse Assistants (CNAs). The CLG-CHWI's specialized tracks also support this continuous learning and are added based on need expressed by CHW workers. These tracks include chronic health and diabetes, Perinatal Hepatitis C, Genetics, and Mental Health. These trainings arm CHWs with knowledge to support pregnant and postpartum women in particular with their unique needs, including families with special child health needs, but also for the general population.

In the Spring of 2023, NJDOH established the CHW Hub at Acenda, who will lead deployment strategies in integrating CHWs into health and care teams to assist in addressing mental health, substance use disorder, and other chronic conditions found in the community. The CHW Hub will give trained CHWs access to numerous employment opportunities throughout the state.

NJDOH continues to offer Rutgers ECHO training series. This information gives doulas and CHWs the training needed to support the MCH population in service navigation amidst COVID and other social and economic stressors. NJDOH ECHO sessions included information to address social needs that COVID-19 exacerbated within vulnerable communities. This information gives doulas and CHWs the training needed to aid the MCH population in service navigation amidst the COVID-19 pandemic. Presently, the Rutgers ECHO series is ongoing in conjunction with our CLG-CHWI.

Millions of pregnant and parenting people are diagnosed with mood disorders, anxiety, depression, post-traumatic stress disorder, substance misuse, or other maternal mental health issues yearly. These issues are much more likely to affect women of color. TVP launched the Alma program in 2023, which is an evidence-based peer mentoring program created with and for new and expectant mothers experiencing depression, anxiety, and substance use disorders. Establishing Alma in NJ will provide new and expectant parents with evidence-based knowledge, skills, and support from peer mentors who have faced similar challenges. By providing tools that can be locally adapted to meet the needs and elevate expertise within

communities, the Alma Expansion project aims to improve maternal mental health and eliminate racial disparities in health outcomes through, program delivery support, an expanded focus on substance use, and a focus on advocacy to sustain the Alma Program in NJ.

Additionally, informed by the recommendations made through the FASD Prevention and PPD-MD evaluation projects, TVP is drafting a new RFA for the aforementioned programs. PPD-MD will relaunch in 2024, and the FASD program in 2025.

Through HWHF and all the aforementioned interventions and activities, TVP will continue to develop partnerships with community-based maternal and child health providers/agencies with proven capabilities in implementing activities/interventions within a targeted community and the capability to focus on reproductive-age women and their families.

Moreover, through the New Jersey Family Planning League (NJFPL), which is a direct grantee for Title X (CDC federal funding), NJ TVP will continue to provide access to quality family planning and related health services for all New Jerseyans who need them, regardless of identity, income, or insurance status.

### Plan for the Application Year NPM # 14:

#### National Performance Measure 14:

Plans for the upcoming year to address NPM #14 include:

- Promoting Mom's Quit Connection for Families (MQCF) to expand reach to pregnant people, parents, and caregivers of young children in NJ.
- Increasing Capacity for Direct Service in NJ.
- Maintain MQCF's existing services statewide.
- Promote onsite trainings, orientations, and webinars to maternal and child health professionals in Central and Northern NJ.
- Preventing relapse after delivery;
- Continue the development of the smoking cessation interactive app using Quit for Kids texting support program that provides customized messaging and interactive activities from the first trimester through the postpartum period. QFK uses a "concierge" concept that tailors messaging to personal, emotional, social, and environmental issues happening in the client's life throughout and beyond her pregnancy.
- Continue to offer Relapse Prevention counseling to all clients.

# Perinatal/Infant Health - Annual Report

The domain of Perinatal/Infant Health sets the trajectory of the health of a child throughout the Life Course. NJDOH has identified the following State Priority Needs (SPN) of Reducing Black Infant Mortality and Improving Nutrition & Physical Activity and selected the related NPMs 4 (Breastfeeding) and 5 (Infant Safe Sleep) because of the Five-Year Needs Assessment process. NJ has implemented several evidence-based strategies related to NPM 4 & 5 which impacts several NOMs (4, 5, 6, 8, 9.1, 9.5).

## **Annual Report - NPM 4:**

Percent of infants who are ever breastfed and Percent of infants breastfed exclusively through 6 months.

Promoting breastfeeding has been a long-standing priority for FHS. Breastfeeding is universally accepted as the optimal way to nourish and nurture infants, and it is recommended that infants be exclusively

breastfed for the first six months. Breastfeeding is a cost-effective preventive intervention with farreaching effects for mothers and babies and significant cost savings for families, health providers, employers, and the government. Breastfeeding provides biologically normal, appropriate nutrition and encourages normal infant development. This form of nurturing is especially important considering the lack of breastfeeding increases the risk of disease and obesity. FHS has developed multiple partnerships to strengthen breastfeeding-related hospital regulations, promoting breastfeeding education, training, and community support.

In 2022, in collaboration with TVP, WIC, and SNAP-ed within the NJDOH released the Breastfeeding Strategic Plan (BSP). Presently, TVP staff sit on the committee that partakes in the implementation of the BSP. The Title V Director also secured funding from the FY24 Governor's budget for dedicated staff to lead implementation of the BSP. A statewide coordinator was hired effective March 2024, and a project associate shortly after.

ESM 4.1 (Increase the Percentage of Births in Baby-Friendly Hospitals) was selected for its positive impact on NPM #4 and NJ's ongoing efforts to promote the Baby-Friendly Hospital Initiative and its ability to monitor breastfeeding rates from birth certificate data and the mPINC Survey.

According to the Centers for Disease Control and Prevention (CDC) 2021, National Immunization Survey Breastfeeding Rate Report Card, NJ rates for newborns ever breastfed in 2019 was 82.5% (NPM 4A). NJ breastfeeding rates in four categories of interest from 2018 to 2020 are depicted in the table below.

Categories	2018	2019	2020
Infants who were ever breastfed	81.7%	82.5%	86.6%
	36.8%	41.2%	43.3%
Infants who were exclusively breastfed through 3 months			
Infants who were breastfed at 6 months	59.8%	55.4%	61.1%
Infants who were exclusively breastfed through 6 months	22.5%	23.4%	25.1%
Infants who were breastfed at 12 months	34.5%	33.8%	38.7%

All breastfeeding rates in New Jersey increased annually among babies born in 2018-2020 in all five categories. The greatest improvement was seen in the rate of breastfeeding at six months – an increase of 5.7 percentage points.

	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Percent of infants who ever breastfed	81.6	82.0	82.0	83.9	82.8	88.8	88.7	81.7	82.5	86.6%
Percent of infants breastfed exclusively through 6	22.3	16.7	23.1	24.8	24.4	22.8	27.7	22.6	23.4	25.1%

months					

Notes - Source – the CDC's National Immunization Survey.

<a href="http://www.cdc.gov/breastfeeding/data/NIS\_data/">http://www.cdc.gov/breastfeeding/data/NIS\_data/</a>; <a href="mailto:DNPAO Data">DNPAO Data</a>, <a href="mailto:Trends and Maps: Explore by Location">Trends and Maps: Explore by Location</a> / CDC

DOH has supported Baby-Friendly<sup>TM</sup> Hospital designation through training, technical assistance, and mini-grants. The Baby- Friendly Hospital Initiative (BFHI) is a global program launched by the World Health Organization and the United Nations Children's Fund to encourage and recognize hospitals and birthing centers that offer optimal care for infant feeding and mother/baby bonding. BFHI recognizes and awards birthing facilities that implement the Ten Steps to Successful Breastfeeding and follow the International Code of Marketing of Breast-milk Substitutes. Thirteen NJ hospitals have earned the "Baby-Friendly" designation.

NJ hospitals participate in the Maternity Practices in Infant Nutrition and Care (mPINC) Survey, a national survey of maternity care practices and policies conducted by the CDC every two years, beginning in 2007. In 2020, 40 of 49 (82%) eligible hospitals participated in the mPINC Survey, which examines best practices and policies in maternity care to improve breastfeeding outcomes. Various domains of health, encouraging behaviors for breastfeeding are examined such as immediate postpartum care, rooming in, feeding and educational support, discharge support and institutional practices which help set a birthing parent up for success in breastfeeding. Each state was given a score, from 1-100, based on the characteristics present in birthing hospitals. and the total score was 82 (above the national score of 81).

## Existing breastfeeding-related programs:

Presently, the WIC program provides breastfeeding promotion and support services for WIC participants through grants to all 16 local WIC agencies. International Board-Certified Lactation Consultants (IBCLC) and breastfeeding peer counselors provide direct education counseling and support services, literature, and breastfeeding aids, which include breast pumps, breast shells, and other breastfeeding aids. WIC staff conducts the Loving Support® through the Peer Counseling Breastfeeding Program. Moreover, WIC breastfeeding staff conducts professional outreach in their communities and education to healthcare providers who serve WIC participants. Close collaboration between Maternal and Child Health Services (MCHS), WIC Services, and the Office of Community Health and Wellness is ongoing. All three programs, in addition to the Office of Minority and Multicultural Health, have an interest in breastfeeding protection, promotion, and support and have similar constituencies. This is best evidenced by the rollout of activities included in the State's Breastfeeding Strategic Plan, led by the State's Breastfeeding Coordinator and her support team.

Through the HWHF initiative, TVP implements community-level programs that promote breastfeeding and potentially address persistent racial and ethnic disparities. For instance, one of the target outcomes of HWHF is, increasing exclusive breastfeeding. Additionally, to address the racial/ethnic disparity in breastfeeding rates, implementing breastfeeding support and education to non-traditional audiences as a mechanism to increase support for NH-Black and Hispanic women is one of the interventions/strategies of HWHF. Moreover, CHWs, postpartum doulas, and their supervisors receive breastfeeding education

through multiple trainings, educational sessions, and professional development opportunities to become CLCs and IBLCs. Considering that breastfeeding is a "family affair", fathers' and other family members' involvement in the process is a puzzle piece that is supported by the HWHF initiative through its focus on non-traditional audiences.

### Annual Report NPM #5 (infant safe sleep)

NJ TVP utilizes block grant funding to fund the Sudden Infant Death Syndrome Center of New Jersey (SCNJ). SCNJ provides bereavement support to families whose infants died suddenly and unexpectedly, often of unknown causes, analyzes etiologies and risks and contributes findings to the American Academy of Pediatrics policy statement and guidelines for risk reduction, and develops and provides public health education to reduce the risk of Sudden Unexpected Infant Death (SUID), which is inclusive of Sudden Infant Death Syndrome, Ill-defined and Unknown Causes, and Accidental Suffocation and Strangulation in Bed. With respect to risk reduction education, the SCNJ develops and provides educational programs, tools, and methodologies that assist the public, health care, social service, childcare, and public health institutions, programs and providers, faith- based communities, home visiting programs, doulas, community organizations, and other systems that interface with parents and other caregivers. The SCNJ also identifies disparities in the adverse social and health determinants that increase the risk of SUID and contribute to disparities in rates and collaborates with the public health systems that address these factors. In working with all programs with the shared goal of reducing infant mortality, the SCNJ has developed the access and trust needed to raise knowledge of safe infant sleep and other riskreducing behaviors. In association with the work of the SCNJ, New Jersey's SUID rate dropped from 0.61 per 1000 live births in the pandemic year 2020 to 0.52 in 2021 (CDC WONDER). New Jersey's 2021 SUID rate was nearly half the national rate of 0.99 and ranked second lowest in the US for all reported states (CDC WONDER). The Black NH rate, along with one other state with an equivalent rate, was the second lowest of all reported states in that group, and the White NH rate was the lowest of all reported states in its group. However, although the SUID rates for New Jersey's population groups compared favorably to national data and relative to other states, racial disparity continues to be evident across states and in summary national data. Nationally, from 2020 to 2021 the disparity in rates rose, but for New Jersey, the disparity was reduced from 2020 to 2021. The SCNJ works to identify and address contributory factors. It collaborates with all programs working to address infant mortality and the adverse social and health determinants that contribute to it. TVP plays a key role in monitoring the activities and ensuring they respond to New Jerseyans' needs.

Promoting infant safe sleep was selected as NPM #5 during the Five-Year Needs Assessment process for its importance in reducing often preventable infant deaths and its potential impact on improving NPMs 1, 2, 3, 4, 5, and 6. Sleep-related infant deaths are one of the leading causes of infant death. They have declined since the onset of risk reduction strategies. However, even on its own, the component of SUID identified as SIDS remains the third leading cause of infant mortality behind a) short gestation and low birthweight and b) birth defects.

Due to evidence of the heightened risk of SUID when infants are placed to sleep on side or stomach sleep positions, health experts and the American Academy of Pediatrics (AAP) have long recommended the back sleep position. The back sleep position has been called one of the seven leading research findings in pediatrics in the last 40 years (Goodstein & Ostfeld, Pediatrics, 2017). Although, by definition, SIDS and ill-defined and unknown causes refer to deaths whose etiology has not been identified, the conditions that elevate risk are known. In 2011, 2016, and in 2022, the AAP updated its recommendations to help reduce the risk of SIDS and other sleep-related deaths by incorporating new research findings. The AAP

recommendations for a safe sleep environment include placing infants to sleep on their backs and having the infant share a parent's room but in his/her own sleep space (e.g., crib, bassinet, portable crib, or play yard) that meets current Consumer Product Safety Commission standards. The AAP also recommends that the sleep space contain a firm flat mattress of the type intended for the sleep product and that the sleeping space be free of soft and loose bedding such as bumpers, pillows, and blankets.

Additional recommendations include breastfeeding or the provision of human milk, avoiding overheating, and avoiding tobacco exposure. These expanded, evidence-based recommendations for the first twelve months of life underlie the National Institute of Child Health and Development (NICHD) Safe to Sleep Campaign and that of the SIDS Center of New Jersey. Adverse social and health determinants, including poverty and preterm birth, also increase vulnerability to SUID and are thus incorporated into strategies to reduce risk. Disparities in these adverse social and health determinants contribute to disparities in SUID rates. Research by faculty of the SCNJ contributed to the AAP guidelines both with respect to safe sleep practices as well as adverse social and health determinants.

The selection of ESM 5.1 (Promote Infant Safe Sleep Environments) monitors and focuses on the safe sleep environment (Healthy Sleep), including back to sleep, no co-sleeping, and no soft bedding. There has been an upward trend in the use of back-to-sleep placement.

Table NPM #5	2009	2011	2013	2015	2017	2019	2021	2022
Percent of infants placed to sleep on their backs	65.7	68.9	69.5	70.5	75	73.0	75.2	76.2

Notes - Source - NJ PRAMS. <a href="https://www-doh.state.nj.us/doh-shad/indicator/view/SafeSleep.Trend.html">https://www-doh.state.nj.us/doh-shad/indicator/view/SafeSleep.Trend.html</a>

In 2004, 60.6% of infants were placed to sleep on their backs. By 2017 the percentage of infants placed on their backs increased to 75%, surpassing the Healthy New Jersey 2020 NJ target of 74.1%. For 2018-20, the target fell within the 95% confidence interval of each year's achieved percentage. In 2022, the percentage rose to 76.2%. In 2004, 43.7% of Black NH and 69.8% of White NH infants were placed supine. For 2017-2020, the percentage of Black NH, and White NH infants placed on their backs surpassed the individual target goals of 53.7% for Black NH and 83.7% for White NH established by Healthy New Jersey 2020. In 2021, 57.4% of Black NH and 87.2% of White NH were placed supine to sleep. In 2022, compliance rose: 58.1% of Black NH and 84.8% of White NH were placed supine.

The SCNJ's extensive train the trainer presentations and educational tools for the public, health care, social service, public health, and childcare providers, home visitors, community and faith-based organizations and others cover all aspects of risk reduction, including how to identify and resolve barriers to compliance and how to discuss information respectfully. Although there was improvement in each racial group and despite New Jersey having among the lowest SUID rates in the U.S., including for each racial group, there are enduring racial disparities in the reported use of back-to-sleep. Safe sleep education is essential, however, factors apart from informing a parent also play a role in choosing supine sleep, as a long history of research has demonstrated. In 2019, 92% of Black NH and 96% of White NH adults completing the PRAMS survey reported that a provider recommended the back to sleep position (Huber R et al., Midwifery, 2024). The most recurring provider contact for the first year of life is the pediatrician. In its provider education, the SCNJ advises that safe sleep be part of the discussion at every visit or at every opportunity.

The SCNJ also works with communities directly including through live webinars that are scheduled through community organizations such as childcare centers and faith-based communities. Potential challenges to safe sleep messaging are addressed in these forums, as well. For a provider to increase not only knowledge but also compliance, recipients respond best to providers with whom they perceive a relationship of trust. Absent that, education may not change behavior. The intimacy of a home visit, whether by doulas, community workers or nurses, helps facilitate such relationships. Therefore, the SCNJ also provides safe sleep education to such groups as Healthy Women, Healthy Families and the Universal Nurse Home Visiting Program (Family Connects), doulas and midwives.

Adverse social and health determinants may also play a role in compliance disparity. These determinants include poverty, smoke exposure, preterm birth, the absence of breastfeeding or human milk, preconception health challenges, including in dental care, inadequate or absent prenatal care, diminished access to pre-conceptional healthcare, implicit bias, and systemic racism. For example, preterm birth increases the risk of SUID, rising to a four-fold greater risk for those born between 24 and 27 weeks of gestation (Ostfeld et al., Pediatrics, 2017). Median household income is inversely correlated with SUID rates (Ostfeld & Hegyi, SPR-PAS, 2019). In 2020, 36% of Black NH vs 11% of White NH children in NJ received public assistance (Annie E. Casey Foundation, Kids Count). in 2021, New Jersey's Gini index of income inequality was at its highest (NJSHAD). Poverty poses challenges to safe infant sleep in multiple ways including a greater use of non-parental care (Holochwost SJ, Dev. Rev., 2020).

Intergenerational education is important to NJ's SIDS-reduction strategy. To broaden access to safe sleep beyond traditional caregivers, the SCNJ created a high school student ambassador for safe sleep curriculum for high school students in <a href="https://higher-risk.communities">higher-risk communities</a>, and it was effective in increasing their knowledge of back to sleep and their ability to educate adults in their communities. With schools now out of COVID-related restrictions, the SCNJ will seek to extend this initiative. Finally, despite the proven risk of prone sleep, interpretation of risk can be idiosyncratic. A well-intentioned grandparent may not support their adult children in the use of supine sleep. "I put all of my babies to sleep on their tummies, and they were just fine," is an often-repeated comment that underscores the challenge in public health education. When one does not comply with evidence-based recommendations, be they dietary or exercise advice, seatbelt wearing, or back to sleep, the refusal does not automatically elicit the worst-case outcome. Working through these challenges has resulted in increased compliance over time and a low SUID rate in NJ for all groups relative to their national and state counterparts.

To promote infant safe sleep (NPM #5), NJDOH has supported the evidence-based strategies of the American Academy of Pediatrics, the NICHD's <u>Safe to Sleep</u> Campaign, the activities of the SIDS Center of New Jersey (SCNJ), <u>www.facebook.com/sidscenternj/</u>, and <u>www.rwjms.rutgers.edu/sids</u>, and the work of the Sudden Unexpected Infant Death Case Review Workgroup which includes representation from the SCNJ. To improve the surveillance of infant safe sleep practices, TVP conducts the PRAMS survey, which includes questions on infant safe sleep, and participates in the SUID-CR Workgroup.

The SCNJ is a program funded by the TVP program to Robert Wood Johnson Medical School (RWJMS), a part of Rutgers, The State University of New Jersey, New Brunswick, and is based both at RWJMS and the Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center, Hackensack. SCNJ was established in 1988 through the SIDS Assistance Act. The SCNJ's missions are to: 1) provide public health education to reduce the risk of sudden infant death, 2) offer emotional support to bereaved families, and 3) participate in efforts to learn about possible causes of and risk factors associated with sudden unexpected infant deaths, best practices for providing safe sleep education and other risk-reducing messages and identifying systemic challenges and barriers. Research by the SCNJ faculty has contributed

to the identification of risk factors and risk-reducing strategies. The SCNJ provides consultation to other States in the service of risk reduction.

The SCNJ develops novel safe sleep interventions and tools to educate providers and the public including parents, grandparents, physicians, nurses, the childcare community, hospitals, clinics, first responders, schools, social service agencies, home visiting programs, doulas, and faith-based communities. It provides safe sleep education for the Division of Child Protection and Permanency, Managed Care, Federally Qualified Health Centers, the Universal Nurse Home Visiting Program, Healthy Women Healthy Families, childcare programs, first responders, programs managed by the Maternal and Child Health Consortia, and other groups.

The SCNJ also works with programs to review their safe sleep curricula and websites and to create bespoke tools such as safe sleep checklists. Most recently these activities have involved the Family Connects program. In addition to live lectures, including medical grand rounds, and lectures in Spanish as well as English, examples of the SCNJ tools and resources the SCNJ created to promote provider and parent knowledge include SIDS Info, its free mobile phone app in English and Spanish with voiceover to eliminate any concerns about literacy, education postcards in multiple languages, recorded seminars for nurses with continuing education credits, and other virtual resources such as public service announcements, and live and on-demand webinars in English and Spanish. In the current grant cycle, the SCNJ is distributing 100,000 English and 20,000 Spanish postcards with double-sided safe sleep messaging to hospitals, clinics, Family Connects, and other programs. The SCNJ has created a baby onesie with "back to sleep" messaging and provides supplies to home visiting programs, hospitals, health clinics, community organizations, and other public health programs. From July 2023 to January 2024, 18,104 onesies in English and Spanish were distributed among these systems. Nurses report that the onesies make the safe sleep discussion easier to conduct. Parents focus on the item and ask more questions. It also serves to facilitate recollection of the discussion, for iOS and Android devices to enhance the education of parents and providers about safe infant sleep and enable parents and others to have direct access to this information. This novel and interactive tool https://www.facebook.com/SIDSCenterNJ/

### Annual Report – SPM #1 (The percentage of Black non-Hispanic preterm births in NJ)

The selection of SPM #1 (The percentage of Black non-Hispanic preterm births in NJ) during the Five-Year Needs Assessment process recognizes the persisting racial/ethnic disparities in healthy birth outcomes in NJ Infants born prematurely. Premature infants are at the highest risk for infant mortality and morbidity. The percentage of Black preterm births was selected to potentially address the underlying causes of Black infant mortality and the racial disparity between preterm birth rates.

The selection of ESM 5.2 (Promote referrals to evidence-based interventions aiming at reducing Black infant mortality) was selected for both SPM # 1 and 7.

Table SPM1 Percentage of Black, NH prete	erm births in NJ from 2012-2021.
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	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Annual Indicator	12.7	12.8	13.3	13.3	13.6	13.1	13.5	13.8	13.7	13.1
Numerator	1,986	1,930	1,983	1,879	1,852	1,774	1,835	1,803	1,721	1,666

Denominator	15,69	15,06	14,86	14,16	13,63	13,53	13,64	13,04	12,58	12,743
	2	4	4	9	4	0	3	3	7	

Notes - Source - Birth Certificate data from the SHAD system <a href="https://www-doh.state.nj.us/doh-shad/">https://www-doh.state.nj.us/doh-shad/</a>

Improving maternal and infant health and reducing Black, NH infant mortality is a priority within the NJDOH/FHS. Key maternal and child health indicators (including low birth weight, preterm births, and infant and maternal mortality) have not improved significantly over the last decade in New Jersey, and significant racial and ethnic disparities persist.

In 2023, preterm birth affected about 1 of every 11 infants born in the US. New Jersey's overall very preterm birth rate (< 32 weeks) decreased from its peak of 1.8% in 2006 to 1.3% in 2021 and, among singletons, the rate declined from 1.4% in 2000 to 1.1% in 2021. NJ's preterm birth rate (< 37 weeks) was 9.3%. However, racial, and ethnic disparities persist. During 2020-2022 (average) in New Jersey, preterm birth rates were highest for black infants (12.8%), followed by American Indian/Alaska Natives (10.1%), Asian/Pacific Islanders (8.6%) and Whites (8.5%). Black infants (12.8%) were about 2 times as likely as White infants (8.5%) to be born preterm during 2020-2022 (average). In the United States, prematurity/low birthweight is the second leading cause of all infant deaths (during the first year of life) and the leading cause of infant death among black infants. To address these disparities and reduce the preterm birth rates, the TV Reproductive and Perinatal Health Services Team implement the Preterm Birth Prevention Program (PBPP). In collaboration with TVP staff, during SFY24, the PBPP accomplished the following:

- Designed and launched a doula-focused survey to identify potential information barriers and opportunities for partnership.
- Created new markers in the Perinatal Risk Assessment (PRA) to identify patients at risk for preterm delivery and began working on a self-service tool based on data pre-populated sections of the PRA.
- Distributed 539 To-Go Kits with health monitoring tools (e.g., blood pressure cuffs, odometers), self-care resources, and health information referral pamphlets to patients with specific chronic conditions who have been identified as being at risk for preterm delivery.
- Distributed over 3,330 flyers about clinical services to prevent preterm birth to providers, administrative staff, and birthing people across the State.
- Engaged with more than 12,000 unique accounts via social media platforms LinkedIn and Instagram.
- Hosted 21 community events that engaged 851 community members and attended 58 professional meetings and events providing information that focused on health risks for preterm delivery and resource allocation in NJ Communities.
- Designed and planned new educational workshops and whole-health events for birthing people with complex care needs (e.g., cardiovascular diseases, diabetes, hypertension, and chronic behavioral health needs) at risk for preterm delivery.

The objectives for SFY24 are in accordance with Healthy People 2030 objective, and are as follows:

• Between 10/2023 and 09/2024, PBPP staff will create or leverage three to five provider-focused resources (such as toolkits, surveys, and provider-focused presentations) to support their efforts in

- providing timely information about preterm birth prevention and available treatment options (e.g., vaginal progesterone cream, cerclage, and education).
- Between 10/2023 and 09/2024, PBPP will host at least four consumer-facing events and at least four Clinical Leadership meetings to develop additional resources and services for future preterm birth prevention service implementation.
- Between 10/2023 and 09/2024, PBPP staff, using the Perinatal Risk Assessment (PRA) data, will identify at least 300 individuals who are eligible for preterm birth prevention services in Cumberland, Mercer, Atlantic, Gloucester, Hudson, and Essex counties, which are 6 of the 12 counties with the highest rates of preterm birth in the state.
- Between 10/2023 and 09/2024, PBPP will create at least two statewide clinical service best practice standards and pilot these resources in collaboration with home visiting programs, FQHCs, doulas, and providers in the focus areas.

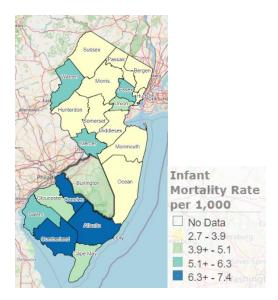
Annual Report – SPM #7 (The rate of Black Infant Mortality in NJ per 1,000 Live Births)

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Annual Indicator	11.4	10.8	8.7	10.6	8.7	9.7	10.0	9.4	8.8	8.5	9.1	7.8
Numerator	182	168	136	159	129	137	136	127	120	111	114	100

Notes - Source - Birth Certificate data from the SHAD system https://www-doh.state.nj.us/doh-shad/

In 2021, the Black, NH infant mortality rate in NJ was 7.8 compared to 2.2 per 1,000 Live Births for White, NH infants. The Hispanic infant mortality rate was 3.7 per 1,000 Live Births. Disparities exist between NJ counties and municipalities in terms of Black Infant Mortality rates and other health outcomes. Counties such as Atlantic, Camden, and Cumberland have high Black Infant Mortality rates (Figure 17). To tackle these disparities, TVP continues to implement HWHF in the communities.

**Figure 17.** Infant Mortality by NJ Counties, 2011-2021



Data Source: New Jersey State Health Assessment Data

There are many potential causes of these disparities, but recent research has highlighted the effects of social determinants of health such as economic disadvantages (i.e., underemployment, or unemployment), limited education (e.g., low educational attainment), environmental barriers (e.g., housing instability, structural racism), and social/behavioral factors (e.g., nutrition and exercise) as major contributors to health outcomes. Addressing these social determinants of health requires a comprehensive, system-level transformation that begins at the community level.

To better align the ESM with our current initiatives, ESM 5.4 (Number of individuals trained to become community- based doula) was selected. Through the New Jersey Doula Learning Collaborative, the professional home for community doulas in NJ, TVP seeks to reduce maternal and infant mortality and eliminate racial disparities in health outcomes. The NJ Doula Learning Collaborative provides training, workforce development, supervision support, mentoring, technical assistance, direct billing, and sustainability planning to community doulas and doula organizations throughout the State of NJ. The NJ Doula Learning Collaborative focuses on developing and supporting the doula workforce that delivers doula care to NJ's Medicaid and CHIP members as enrolled NJ FamilyCare providers. They recruited, trained, and certified 32 Perinatal Community Health Workers (aka community doulas) since its inception in 2022 to further support birthing individuals and potentially decrease the infant mortality rate. These community doulas help birthing individuals navigate the healthcare system, access needed services, and improving adverse birth outcomes. The trained doulas provide equitable and culturally responsive care to pregnant people during pregnancy, birth, and postpartum, potentially lowering maternal and infant health complications rates. Multiple studies have shown that doula care can improve maternal and infant health outcomes; reduce preterm births and low birthweight infants; lower rates of cesarean sections; and increase rates of breastfeeding by amplifying pregnant people's voices and listening to their needs.

# NPM 4: Percent of infants who are ever breastfed and Percent of infants breastfed exclusively through 6 months.

Efforts to promote Baby-Friendly Hospital Initiative (BFHI) designation through training, technical assistance, and mini-grants will continue to promote NPM 4. Surveillance through the Birth Certificate file and the mPINC survey will continue to identify areas of potential improvement.

The selection of ESM 4.1 (Increase Births in Baby-Friendly Hospitals) will monitor progress in promoting breastfeeding policies and practices in hospitals which should lead to an increase in NPM #4 (Breastfeeding). Many hospitals employ IBCLCs and provide early support and information to breastfeeding mothers. However, this work requires a commitment from the entire organization to implement supportive breastfeeding policies and practices.

The Breastfeeding Strategic Plan's primary purpose is to provide a roadmap to identify and foster policy, environmental, and system changes to increase breastfeeding initiation, duration, and exclusivity in NJ. Since the release, TVP staff has been actively involved in the committee and worked on materials to support the implementation of the strategic plan. With the hiring of dedicated breastfeeding coordination staff, TVP staff will remain involved in the implementation process of the strategic plan. WIC will continue to provide breastfeeding promotion and support services to pregnant and breastfeeding women who participate in the program.

Through HWHF, TVP continues to fund multiple community-level organizations to implement breastfeeding education and training, primarily focusing on non-traditional audiences such as fathers, grandmothers, teens, etc. These breastfeeding education and training programs are given to increase the focus and support for breastfeeding success. The initiative aims to increase breastfeeding rates throughout the State with a high focus on Black mortality rates. Breastfeeding is known to have numerous protective factors for newborns and birthing parents. Increasing the rate of breastfeeding in marginalized and underrepresented groups will increase the likelihood of infants reaching their first birthday. CHWs are key stakeholders in educating birthing and new parents on breastfeeding.

CLG-CHWI is monitored and evaluated by TVP staff. TVP staff will continue to implement breastfeeding training in partnership with the Perinatal Foundation. The breastfeeding education training for CHWs is a course designed to increase the basic knowledge of breastfeeding and cultural nuances as it pertains to breastfeeding in the Black community. The curriculum is taught using a reproductive justice and trauma-informed framework. Learners will acquire skills in the anatomy and physiology of lactation, counseling, troubleshooting common breastfeeding challenges and solutions, approaching the subject of breastfeeding, and more. Additionally, attendees will be educated on how to support breastfeeding in unique populations, including preterm birth and parents with special needs. The training consists of five modules that cover the Black Breastfeeding Experience, Global Health, the Influence of Formula, the Lactation Landscape, and Feeding Choice.

## Plan for the Application Year - NPM 5 (Percent of infants placed to sleep on their backs)

The public health interventions and activities depicted in the section pertaining to safe sleep through the SCNJ are supported through grant funding from TVP. TVP plays a key role in monitoring these activities and ensuring improvement in infant health outcomes in NJ.

In 2021, the most recent year with finalized SUID rates, NJ overcame the 2020 rise in its SUID rate that was associated with the onset of the COVID-19 pandemic. In 2021, the NJ SUID rate dropped from 0.61

per 1000 live births in 2020 to 0.52, based on data reported by the CDC WONDER. New Jersey's 2021 SUID rate of 0.52 was nearly half the national rate of 0.99 and ranked second lowest in the US for all reported states. In addition to poverty, other adverse social and health determinants that elevate risk and are more evident in the context of Black NH infants include smoke exposure, preterm birth, the absence of breastfeeding or human milk, untreated preconception health challenges, including in dentistry, inadequate or absent prenatal care, diminished access to pre-conceptional healthcare, implicit bias, and systemic racism.

Three factors are relevant in examining the next steps for intervention: 1) the need to better address the systemic challenges that disproportionately and disadvantageously affect well-documented health and social risk factors for SUID within the non-Hispanic Black population; 2) through more committed policy and legislation, the need to correct institutional loopholes that diminish the provision of comprehensive and consistent safe sleep education despite enduring efforts by public health programs charged with reducing the risk of SUID; 3) the need to further assess and address root causes in the well-documented disparities throughout the US in the adoption of back to sleep and other guidelines despite also well-documented awareness of these guidelines.

With respect to the first step, while it is beyond the SCNJ's scope of work to address larger social challenges, it does and will continue to participate in forums such as the Perinatal Quality Collaborative Health Disparities Work Group and Nurture NJ to bring attention to the role of these issues in elevating the risk of SUID and of disparities in rates and to collaborate in finding solutions. Since so many distinct topics fall under the umbrella of adverse social and health determinants, (i.e, structural racism, implicit bias, neighborhood crime, food insecurity, poverty, inadequate prenatal care, preterm birth, and smoking), the SCNJ also works with programs that focus on specific issues such as Mom's Quit Connection that addresses smoking and the Fetal and Infant Mortality Review committees that help identify adverse social factors.

With respect to the second step, a key requirement is that evidence-based education opportunities that are consistent with the American Academy of Pediatrics guidelines, to which the SCNJ's research has contributed, be available and actively promoted. The SCNJ creates multiple educational methodologies and identifies a range of target audience that include the healthcare community, social service and childcare providers, home visiting programs, community, and faith-based systems, first responders, and the public. In addition to pediatricians, the SCNJ educates obstetricians who help raise awareness of risk factors that matter during pregnancy, gynecologists who connect with the community of grandmothers and serve as a trusted resource for health information, family practitioners, nurses, doulas, and midwives. The SCNJ also uses tools to supplement education both for providers and the public. Examples include its safe infant sleep mobile phone app, on-demand webinars, printed material, videos, public service announcements, and onesies with safe sleep messaging, Infographics leading to many of these tools is on SCNJ website listed at the end of this document. Information is provided in multiple languages. The SCNJ identifies populations at greatest risk and agencies that are critical to the risk reduction education of those populations as well as systems working with all infants.

With respect to the third step, knowledge of risk factors does not automatically lead to changes in behavior or even to sustaining compliance over time. A large body of research has confirmed the enduring disparity in accepting some safe sleep recommendations and provides insights into the historical, cultural, and systemic bases for many of these decisions. The SCNJ will continue to apply this knowledge in its outreach programs and work with parents and communities to improve the acceptance of recommendations. Reaching grandparents and others in a family who help take care of an infant thus

becomes an essential part of the educational mission. The SCNJ will continue to provide respectful multigenerational education through faith-based communities and other methods to expand its effective student education program.

The work of the SCNJ is supported through grant funding from TVP. In addition to the systemic approaches described, plans for the coming year to promote safe infant sleep include continued education through the SCNJ, MIEC Home Visiting Program, and the Sudden Unexpected Infant Death Case Review Workgroup, including representation by the SCNJ. Staff from the MIEC Home Visiting Program have all been trained by the SCNJ and will promote the infant safe sleep message during their visits to over 7,000 families annually in NJ. The SCNJ is now planning a new cycle of staff education. As described above, the new Universal Nurse Home Visiting Program is also receiving education services and materials from the SCNJ. The SCNJ's baby onesies with back-to-sleep messaging will be provided to home visitors and hospitals, and resources are being sought for more. NJDOH has supplemented TV funding with additional state funding specifically for additional onesies in other languages and sizes.

The SCNJ also continues to develop direct public education tools, such as SIDS Info, its free and nationally recognized mobile phone app in English and Spanish, social media platforms, on-demand webinars and short videos. Tools such as these enabled families who had diminished contact with providers during the pandemic to directly access safe sleep education. The SCNJ has updated SIDS Info to include the new 2022 American Academy of Pediatrics additions to its risk reduction guidelines. It will continue to be available in English and Spanish with voice-over to overcome literacy challenges. The SCNJ will continue to have a broad target for its education outreach such as institutions (i.e., schools, hospitals, clinics, hospital grand rounds programs, public health programs), organizations (i.e., WIC, HWHF grantees, NJAAP, Maternal, and Child Health Consortia, Nurture NJ), providers (i.e., pediatricians, obstetricians, nurses, social service providers, home visitors, clergy, community workers, doulas, first responders), and the public (i.e., baby fairs, community programs). Where needed, it will create new tools to serve particular groups. A high-school student ambassador for a safe sleep program developed by the SCNJ was found effective, thus supporting plans for broader adoption. While this initiative was delayed during the pandemic due to the challenges faced by public schools, it is being considered for a new project. SCNJ activities also include participation in implicit bias initiatives and inclusion of this topic in its education programs. The SCNJ has updated its Infant's Bill of Rights to serve as a framework that can potentially address the risk factors in addition to safe sleep that both the AAP guidelines and a large body of research support as contributory to fatalities. In recognition of New Jersey's diversity, the SCNJ developed educational materials that are translated into English, Spanish, Haitian-Creole, Farsi, Arabic, and Portuguese. Dari has been added to serve Afghan refugees. Many of the SCNJ resources can be accessed from the SCNJ social media site: [68] and website: https://www.facebook.com/SIDSCenterNJ/@ and website: @www.rwjms.rutgers.edu/sids. Information about these resources will continue to be widely disseminated.

# Plan for the Application Year SPM 1 (The percentage of Black non-Hispanic preterm births in NJ)

In partnership with the Maternal Health Innovation (MHI) team and the NJ Maternal Care Quality Collaborative (MCQC), TVP will continue to co-lead multiple activities aiming at reducing preterm birth rates of untimely death for non-Hispanic Black and Hispanic infants. Through the Preterm Birth Prevention Program (PBPP), TVP staff, in collaboration with key stakeholders, will create, disseminate, and evaluate provider-specific resources on preterm birth prevention for identified patients. They will convene multidisciplinary meetings with stakeholders to assess the challenges, opportunities, and overall impact of identified preterm birth prevention services and resources. They will use data from varying

sources and improve timely information sharing to support and identify patients in need of preterm birth prevention services. They will distribute and provide information about preterm birth prevention services and resources. Lastly, they will compile data from activities for recommendations, reports, and presentations to NJDOH leadership and partners. Moreover, TVP, in collaboration with MHI, will continue to support the design of new educational workshops and whole-health events for birthing people with complex care needs (e.g., cardiovascular diseases, diabetes, hypertension, and chronic behavioral health needs) at risk for preterm delivery.

#### Plan for the Application Year SPM 7 (The rate of Black Infant Mortality in NJ)

The HWHF Initiative will continue to develop partnerships with community-based maternal and child health providers/agencies with proven capabilities in implementing activities/interventions within a targeted community. Specifically, with a focus on reproductive-age women and their families. The HWHF initiative will continue to focus on postpartum care through the novel postpartum doula care municipality program launched this year. Moreover, through the HWHF initiative, TVP will provide evidence-based lactation education to birthing individuals and their social network (e.g., fathers, grandparents, siblings, etc.). The Doula Learning Collaborative will continue to train community doulas and educate them on how to enroll in NJ FamilyCare fee-for-service and the Managed Care Organization's process to become NJ FamilyCare Community Doula providers. They will continue to provide training, workforce development, supervision support, mentoring, technical assistance, direct billing, and sustainability planning to community doulas and doula organizations throughout the State of NI.

#### Child Health – Annual Report

The domain of Child Health includes the State Priority Needs of #3 Improving Nutrition and Physical Activity and the selected National Performance Measures of #6 Developmental Screening. NPMs #6 was selected during the Five-Year Needs Assessment process for their impact on overall child health and wellness and the evidence-based strategies that NJDOH and its partners implemented.

Annual Report- NPM # 6 (Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool)

Increasing NPM #6 is an important focus in the domain of Child Health that seeks to improve overall child health and well-being. Early identification of developmental disorders is critical to the well-being of children and their families. It is an integral function of the primary care medical home. The percentage of children with a developmental disorder has been increasing, yet overall screening rates have remained low. The American Academy of Pediatrics recommends screening tests begin at the nine-month visit.

	2011-	2016	2017-	2018-	2019-	2020-
	2012		2018	2019	2020	2021
NDM C. D of al. 111	25.02	22.0	26.1	22.2	22.2	21.1
NPM 6: Percent of children,	25.02	32.9	36.1	32.2	32.3	31.1
ages 9 through 35 months,						
receiving a developmental						
screening using a parent-						
completed screening tool						
compressed servering to or						

Source – National Survey of Children's Health (NSCH) https://www.childhealthdata.org/browse/survey/results?q=9597&r=1 Developmental screening is a required benchmark performance measure for the NJ MIECHV Program. Improving developmental screening practices and policies is an ongoing focus of Home Visiting's continuous quality improvement activities. The NJ MIECHV Program promotes and monitors parents who have completed the child development screening tools (ASQ and ASQ: SE). In SFY 2022, 5,628 NJ MIEC Home Visiting families with young children participated in a parent-led developmental screening across all 21 NJ counties.

The NJDOH, through TVP, is an active interdepartmental partner with the NJ Council for Young Children, the Preschool Development Grant: Birth to Five (PDG B-5), the CDC's NJ "Learn the Signs. Act Early." (LTSAE) Ambassador (housed at the SPAN Parent Advocacy Network and is also NJ's AMCHP Family Delegate), and the NJ Council for Young Children Infant Child Health Committee that has established a priority of improving system connections for children and families with health care providers, community services, early intervention, childcare, home visiting, and early care & education settings. Improvements in early childhood systems continued through the NJ Early Childhood Comprehensive System (ECCS) and Collaborative Improvement and Innovation Network (CoIIN). The focus remains to create universal access to evidence-based developmental screening through the early childhood Connecting NJ (formerly known as Central Intake) system (Help Me Grow Central Access point). Connecting NJ supports linkages and access to programs and services for families within their community. The NJ LTSAE Ambassador activities focus on promoting family-engaged developmental monitoring and screening and referral and connection to services through trainings, presentations, and materials distributed across the state. As the State Parent Lead for the ECCS Impact CoIIN and MIEC Home Visiting programs, the LTSAE Ambassador activities also focus on the priorities of the NJCYC ICHC and support the teams with accessing LTSAE materials as well as with family- engagement activities. NJ's Child Developmental Passport, created in collaboration between the NJ LTSAE Ambassador at SPAN and the ECCS CoIIN team (available in English & Spanish), includes a developmental tracker to empower parents to track their child's developmental screening information.

The selected ESM 6.1 will monitor progress on increasing parent-completed early childhood developmental screening using an online ASQ tool. It will also monitor how well early childhood developmental screening is promoted across the Departments of Health, Children and Families, Human Services, and Education, which will drive improvement in NPM #6 (Developmental Screening). NJ DCF, in collaboration with TVP at NJDOH, implements Early Childhood Comprehensive Systems Prenatal-to-Three Community Grant that focuses on enhancing the early childhood system. This iteration has focused on health integration and promotion of the coordinating system of care of families of young children and creating greater awareness with health providers as they support families with young children. The previous iteration of ECCS (Impact) focused on five communities to test and scale up developmental health promotion and parent-completed early childhood developmental screenings in children under three years old.

The ASQ Enterprise software (Brookes Publishing) is being utilized to add a parent/family portal for easy access to developmental screening and links screening to Connecting NJ hubs. NJ's expanded data system links developmental screenings with all 21 Connecting NJ hubs to enhance the engagement of families not connected to early childhood services/programs. This expansion of the data system could potentially be engaged and linked for additional services and supports as identified, including developmental needs as determined by the completed ASQ. Families receive support and referrals to an array of services, for instance, pediatric primary care and/or other systems partners, including Home Visiting, Healthy Women Healthy Families Community Health Workers, and/or other service providers as determined by the family

and their needs/interests. The referrals and connections provided through the extend to quality Childcare, Early Head Start/Head Start, and Preschool programs. In FY22, the Connecting NJ hubs maintained developmental health promotion, screening, and linkage. There were 1,382 screens completed through the Connecting NJ hubs via the Brookes Publishing Family Access Portal for children 2 months to 60 months. Below is a chart outlining the percentage of children reached by age domain for FY20-22.

ASQ- Family Access Portal Screens completed	FY 20	FY 21	FY 22
Total # of screens	1689	1107	1382
Age of Child	%	%	%
2-12MO	35%	35%	25.9
13-24MO	18%	22%	26.9
25-38MO	16%	19%	21.8
39-50MO	20%	13%	14.9
51-66MO	11%	11%	10.5

#### Child Health - Application Year

Plan for Application Year- NPM# 6 (Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool)

The NJDOH will continue to participate as an active interdepartmental partner with the NJ Council for Young Children (NJCYC), the Preschool Development Grant Birth to Five (PDG B-5), CDC's NJ "Learn the Signs Act Early (LTSAE)." LTSAE Team and the NJ CYC Infant Child Health Committee (ICHC). The ICHC has prioritized improving system connections for children and families with health care providers, community services, early intervention, childcare, home visiting health care, and early care and education settings to support overall child development and well-being. The NJ ECCS Impact CoIIN work informs potential improvements in early childhood systems, focusing on creating universal access to evidence-based developmental screening. The Connecting NJ system (Help Me Grow Central Access Point) supports linkages and access to programs and services for families within their community.

SPAN Parent Advocacy Network will continue to collaborate with the NJ Chapter of the American Academy of Pediatrics on the Early Identification and Referral for Autism (EIRA) ECHO project to educate pediatric practices on the early identification, referral, and care coordination of children with ASD. SPAN is also collaborating on a project with the NJ site for the Autism & Developmental Disabilities Monitoring Network to promote awareness about the importance of parent-engaged developmental monitoring and the early identification of ASD using a validated screening tool in the Newark area.

Grow NJ Kids (GNJK), a Quality Improvement Rating System (QRIS) developed for early learning programs, requires the use of a "state-approved" developmental screening at Level 2 of a 5-level rating. The Implementation of a parent/family portal for easy access to parent-completed early childhood

developmental screenings in children < 3 years old through the ECCS P-3 grant is ongoing. The parent/family portal will permit monitoring of ESM 6.1 (Promote parent-completed early childhood developmental screening) and promote improvement in NPM #6.

NJ has completed significant work to create an aligned early childhood data system through the NJ Enterprise Analysis System for Early Learning (NJ-EASEL). The NJ-EASEL project currently links DOE Statewide Longitudinal Data System (NJ SMART), County/District/State (CDS) reference data, DHS childcare subsidy data (CARES), and DOH birth record data (EBF/VIP) and data from two DCF Home Visiting systems, Healthy Families (FAMS) and Parents as Teachers (PATS).

In future phases, NJ-EASEL plans to integrate DCF childcare licensing information (LIS), DHS Workforce Registry (NJ Registry for Childhood Professionals, a component of the Grow NJ Kids data system), DHS Grow NJ Kids data, DOE staff/workforce data (NJ SMART), DOH Early Intervention System, DOE assessment data (Title 1), DHS cash and food stamp assistance data (FAMIS) and DCF foster care system, and other states early learning and development data collections within the parameters of state and federal privacy laws.

The NJ-EASEL project measures outcome objectives initiated through the Race to the Top Early Learning Challenge RTTT-ELC grant. The NJ-EASEL project shows that early developmental screening directly impacts identifying children and referring them to needed services resulting in positive outcomes for children. The NJ- EASEL integrated data warehouse will serve as the repository through which collected data informs the quality improvement and outreach activities "managed" by GNJK. Overall, NJ-EASEL enables program administrators to provide increased access to high-quality early care and education programs and professionals for NJ's children and families. NJ-EASEL will continue to provide visibility of the collaboration and coordination among Early Childhood Care and Education programs across agencies through the linkages and crossover reports of these programs for participating children.

#### Adolescent Health – Annual Report

The domain of Adolescent/Young Adult Health includes focuses on NPM #9: Bullying (Percent of 9-12th graders who reported being bullied on school property or electronically bullied), NPM #11 (Percent of children with and without special health care needs having a medical home) and NPM #12 (Percent of children with and without special health care needs who received services necessary to make transitions to adult health care). Considering that the reporting on NPM #11 and #12 overlap the two domains of Adolescent/Young Adult Health and CYSHCN, the narrative for NPM #11 and #12 will be presented in this Adolescent/Young Adult Health section and not repeated in the CYSHCN Section. This section serves as the State's narrative plan for the Annual Report and the Application year. Planned activities for the Application year are described, and programmatic efforts have been summarized for the Annual Report year, with primary emphasis placed on the performance impacts achieved. The strategies and activities to address the identified priorities from the Needs Assessment Summary are further described.

### Annual Report - NPM #9 (Bullying)

Improving NPM #9 (Bullying) is an important measure in the domain of adolescent and young adult health and is related to SPN #4, Promoting Youth Development, and SPN #6, Preventing Teen Pregnancy. Bullying can impact both short and long-term physical and emotional health in adolescents and young adults. Bullying can lead to physical injury, social problems, emotional problems, increased risk-taking behaviors, and death. Bullied teens are at increased risk for mental health problems, have

problems adjusting to school, and are connected to absenteeism. Moreover, bullying can cause long-term damage to self-esteem.

The selection of ESM 9.1 (Reduce the percentage of high school students who are electronically bullied) and ESM 9.2 (Reduce the percentage of high school students who are bullied on school property) monitor progress in reducing bullying that takes place on social media and in-person at school, which should lead to a decrease in the percentage of 9-12th graders who reported being bullied on school property or electronically bullied NPM #9.

Through the CAHP, multiple efforts are made to decrease bullying in schools and build the social and emotional learning competencies of bullies and bullied youths. Building youth's capacity for self-awareness, social awareness, self-management, relationships, and decision-making helps build the core skills teens need to refrain from bullying others and bounce back when they are bullied.

According to Collaborative for Academic Social and Emotional Learning, these skills allow children to calm themselves when angry, initiate friendships, resolve relationship conflicts respectfully, and make ethical and safe choices. To develop these capacities, children need to experience safe, nurturing, and well-managed environments where they feel valued and respected; and have meaningful interactions with others who are socially and emotionally competent; and receive positive and specific guidance.

Bullying is a learned behavior that often starts at home. It is learned from older siblings, extended family, and parents and then transferred to school behaviors. Youth who are bullies are at increased risk for substance use, academic problems, and violence to others later in life. Teens who are both bullies and victims of bullying suffer the most serious effects of bullying and are at greater risk for mental and behavioral problems than those who are only bullied or bullies. To tackle the bullying problem at its core, CAHP implements multiple student and parent engagement programs. Parent engagement helps parents and caregivers (PCGs) better understand, support and communicate with their teens which builds protective factors and reduces the impact and incidence of bullying. Connection to a supportive adult has been associated with decreased drug use, delayed initiation of sex, and fewer suicide attempts in teens. Key risk factors for teen decision-making include family-related protective factors such as positive values and norms expressed and modeled by family members and other trusted adults and feelings of connection to groups that encourage responsible behaviors. Teen Speak, one of the parent engagement programs implemented via CAHP, offers skill-building workshops for parents and other supportive adults to help foster critical intergenerational connections and build protective factors in the home and community. Through short, multimedia workshops focused on improving adult-teen communication and in-person facilitated sessions where parents and caregivers can practice new techniques to engage their teens; Teen Speak seeks to reduce harmful behaviors and build strong family relationships. Teen Speak also collects data from participants via pre-surveys, polls during lessons, and a post-retrospective survey. In September of 2023, CAHP released an RFA for our new Statewide Parent and Professional Engagement Program (S-PEP). S-PEP will create a centralized space for PCGs, and professionals to access Teen Speak and MITEY Change (for professionals). Ideally, this will expand and streamline access to PCG and professional education to better care for adolescents in NJ.

In addition to engaging teens and parents directly, youth-serving professional capacity must be improved at the school and community-based level. There is a strong connection between bullying and mental health, and the <a href="National Institute of Health and Human Development">National Institute of Health and Human Development</a> (NICHD) research studies show that anyone involved with bullying—those who bully others, those who are bullied, and those who bully and are bullied—are at increased risk for depression. <a href="NICHD">NICHD</a>-funded research studies also found that, unlike

traditional forms of bullying, youth who are bullied electronically—such as by computer or cell phone—are at higher risk for depression than those who bully them. Even more surprising, the same studies found that cyber victims were at higher risk for depression than were cyberbullies or bully victims (i.e., those who both bully others and are bullied themselves), which was not found in any other form of bullying. These findings are in the NICHD news release: Depression High Among Youth Victims of School Cyberbullying, NIH Researchers Report.

CAHP and grantees have been trained in multiple approaches to working with our most vulnerable youth. Trainings have included, comprehensive youth suicide prevention and safe messaging, mindfulness, youth mentoring, youth-adult partnering, cyber-bullying, effective use of social media, LGBTIAQ inclusivity training, and an intensive Transgender 101 train the trainer, social and emotional learning and trauma-informed care (TIC). Training and technical assistance (TA) occur quarterly. They are required for all PREP, SRAE, and School Health program grantees but are open to all CAH Programs and Program Partners, including schools and community-based organizations where CAH programs operate.

In November 2020, NJDOH was awarded a Garrett Lee Smith (GLS) Tribal/State Youth Suicide Prevention Grant. In addition to providing training and education for suicide prevention, screening, and treatment to youth-serving professionals, the GLS grant launched a statewide implementation of Lifelines Trilogy, comprehensive suicide prevention, intervention, and postvention program. In 2023, GLS provided trainings to 4,383 primary care practitioners, behavioral health clinicians, educators, youth serving professionals and parents/caregivers in multiple clinical and non-clinical trainings. Through 988, GLS funds supported screening for 6,586 youth for suicidal ideation, provided 1,290 referrals and confirmed that 684 youth accessed treatment. GLS sponsored 2 Youth Summits that reached 263 youth and school professionals from over 15 school districts. GLS also funded mini grants at 15 county colleges to support campus wide suicide prevention activities. Finally, GLS began implementation of Lifelines at 5 new school districts including New Brunswick School District, one of the largest school districts in NJ. Through Lifelines thousands of school professionals, community partners and students have been trained with two school districts completing the 24-month training and implementation process and are now fully sustaining Lifelines in their districts. By the end of the grant (November 2025) 15 school districts will have completed the process and sustaining Lifelines in their schools.

Through a comprehensive approach aimed at building the skills, competencies, and capacity of teens, parents/caregivers, and youth-serving professionals, the CAHP seeks to decrease bullying and increase resilient responses to bullying in our schools and communities. The most recent program added to the CAHP roster is Lifelines Trilogy, a comprehensive suicide prevention program with a 5th through 12th-grade curriculum. The curriculum is grounded in SEL and focuses on the importance of asking for help. Three schools have completed training and begun implementing the student curriculum. Thus far, 821 students have received the curriculum materials. Pre and post-test data are being analyzed and will be available in next year's annual report.

### SPN # 6 (Reducing Teen Pregnancy)

## Annual Report SPM 6 (TOP® program, Reducing the Risk, Teen PEP and Lifelines completion)

Simultaneously, to satisfy SPN # 6-Reducing Teen Pregnancy, TVS has selected ESM 9.1 (ESM 9.3: Number of females aged 10-19 who give birth), which monitors progress in reducing teen pregnancy in NJ. The CAHP has adopted the Teen Outreach Program (TOP®), Love Notes, Reducing the Risk, and Teen PEP, all evidence-based models (EBMs) proven to reduce teen pregnancy. From 10/1/22 - 9/30/23, 3,900 students have been actively engaged in the EBMs indicated. Lifelines, like our other EBM's is a

social and emotional learning-based program which has been linked to improved decision making and self-regulation behaviors similar to the other EBMs implemented. Improved SEL is also linked to improved decision-making and healthy relationships and contributes to reducing teen pregnancy. The CAH Programs link teens from diverse backgrounds and groupings within schools and facilitate dialogues that encourage teens to be introspective, connect with their peers, partner with adults, and participate in bettering their communities. Data are collected for all EBMs implemented via pre- and post-surveys delivered to participants that measure sexual health behaviors such as using birth control, barrier contraceptives, and delaying/abstaining from sexual activities. In addition, SEL questions regarding bullying behaviors, teen connectedness, and resiliency are also measured.

Adolescent Health – Application Year

## Plan for the Application Year - NPM #9 (Bullying), SPN # 6 (Reducing Teen Pregnancy)

The CAHP will continue to implement social and emotional learning and parent engagement programs along with virtual activities that provide youth with opportunities to lead and educate their peers. The CAHP will continue to promote the adoption of Evidence-based SEL programs, including TOP®, LifeLines Trilogy, Love Notes, Teen PEP, and the WSCC model in NJ schools. NJDOH has sunset Reducing the Risk (RTR) and has replaced this curriculum with Get Real starting October 1, 2023. In addition, the CAHP will be expanding the reach of Teen Speak statewide through a new RFA S-PEP (Statewide Parent and Professional Engagement Program. Teen Speak currently serves approximately 500 parents statewide and, with the new RFA, will serve increasing numbers of parents over a 4-year grant cycle. CAHP will continue to host the NJDOH Voice of Youth Planning Committee (VYPC) as they plan and implement youth-led virtual programs for their peers. The VYPC has chosen a focus for 2024, Mental Health and Self Care at the 2023 Statewide YAB meeting. Finally, NJDOH will continue to provide training and technical assistance to our grantees and partner organizations that will help youth-serving professionals build their competencies to help provide youth opportunities to avoid bullying as a perpetrator or victim. In 2024, S-PEP will launch a youth professional development training called MITEY Change. Motivational Interviewing Training for Empowering Youth towards Change provides education and resources to enhance professionals' knowledge, skill, and confidence in providing effective and efficient youth risk coaching. Dr. Jennifer Selerno, the developer of Teen Speak, developed this online course.

Children with Special Health Care Needs – Annual Report

The population domain of CYSHCN includes NPM #11 and #12 which were covered in the previous Adolescent / Young Adult Health domain, and SPMs 3, 4 and 5, which impact NOMs 13, 15, 16, 17, 18, 19, 20, 21 and 22.

Annual Report- SPM# 3 Percentage of newborns who are discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening, and have outpatient audiological follow-up documented.

The New Jersey EHDI program has processes in place to help ensure that all children who do not pass newborn hearing screening receive follow up screening in alignment with national EHDI guidelines. These diagnostic audiologic evaluation takes place prior to three months of age for infants and ensures that any child who goes on to be diagnosed with hearing loss is enrolled in early intervention no later than six months of age. Provisional data for 2023 indicates that 78.6% of infants who did not pass their initial newborn hearing screening prior to discharge from the birthing hospitals had a documented outpatient audiological follow-up visit. Since follow-up exams are still occurring on children born at the end of

2023, we expect the rate to increase when final data is available. We anticipate that the final rate will be level with prior years and exceed the target. The program also monitors the follow-up rates by race/ethnicity for disparities in outcomes.

Table SPM #3: Percentage of newborns who are discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening, and had a documented outpatient audiological follow-up visit.

	2017	2018	2019	2020	2021	2022	2023*
Annual SPM#3 Indicator	87.5%	86.1%	82.6%	79.7%	81.0%	87.0%	78.60%
Numerator	1570	1571	1362	1439	1397	1726	1581
Denominator	1798	1824	1648	1804	1724	1984	2012

\*Note – Follow-up reports are still being received for children born at the end of 2023 and the final rate is expected to exceed this rate.

Birthing facilities are required to make at least one contact with families to remind them of the need for follow-up. Additionally, case managers funded by the EHDI program contact families to ensure follow-up visits take place. Barriers to our follow-up efforts include disconnected phone numbers, mail returned undeliverable, and unanswered voicemail messages. Other families do not have follow-up testing completed despite contacts made by the hospital or case manager. Barriers can include lack of insurance, transportation or childcare issues preventing travel to an outpatient audiology appointment, or parents not feeling follow-up testing is important because the child appears to respond to sounds around the home.

In addition to the overall Follow-up Rates, the data are provided by race/ethnicity (Figure 17). While we strive for 100% follow-up and to eliminate racial and ethnic disparities, there are differences across the groups. To reach as many groups as possible, and reduce lost to follow-up, the EHDI program Newborn Hearing Screening brochure is provided to birth facilities to distribute to all families. The brochure is in English and provides information on newborn hearing screening and follow up. QR codes are provided for access to material on Can My Baby Hear, which explains the importance of and the process of newborn hearing screening, and Your Baby Needs Another Hearing Test, which explains the importance of follow up. Both are translated into ten languages and are accessible on the EHDI website.

Total Outpatient Follow-up of Babies that Referred (2023)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Hispanic

75%

White

Black

Asian

Figure 19. Total Outpatient Follow-up of Babies Referred

The EHDI program is responsible for assuring newborn hearing screening goals are met, including ensuring timely and ear-specific audiological follow-up for children that did not pass the initial screening. All outpatient audiologic reporting to the EHDI program continues to be submitted via an EHDI module in the NJIIS registry. The NJIIS program had a complete system rebuild and the EHDI module was also modified to improve the information collected about follow-up contacts to parents.

During 2023, EHDI trained 55 new users on the EHDI reporting module in the NJIIS, which is used by audiologists and other practitioners conducting hearing follow-ups to report outpatient exams. The EHDI program receives approximately 89% of reports entered by providers through this Web-based application and 11% are sent to the program on paper forms. Nancy Schneider, MA, CCC-A, FAAA, trained 38 audiologists and audiology graduate students on how to use the NJ 's online reporting module within the NJ Immunization Information System. NJ DOH continued using HRSA EHDI grant funding for county-based special child health services case management staff to conduct follow-up phone calls to parents and physicians of children needing hearing follow-up.

NJ DOH continued to use HRSA EHDI grant funding for one of the Early Intervention Services (EIS) program's Regional Early Intervention Collaborative's to provide three part-time consultants who specialize in working with Deaf and Hard of Hearing children. The process includes an initial phone conversation with parents of children recently diagnosed with hearing loss to review early intervention services and discuss communication options for these children. The consultants participate in the initial EI family meetings via remote access, using laptops with web-cameras. The consultants served a total of 88 families during this year.

The EHDI Monthly Reconciliation Report is distributed to individual hospitals detailing children still in need of additional audiological follow-up after not passing inpatient hearing screening. These reports serve as a notice to the hospitals of babies who still need follow-up. Additionally, an annual report includes statistics comparing the individual hospitals to statewide statistical average.

An annual report is provided to audiology facilities with feedback on their timeliness of follow-up for children who did not pass their inpatient hearing screening. The report also includes statistics on the timeliness and completeness of the documentation of their results.

The Hearing Evaluation Council, a commissioner-appointed advisory board to the NJ EHDI program, held three meetings this year. The council is made up of physicians (a pediatrician and otolaryngologist), an audiologist, a child of Deaf or Hard of Hearing adults, a member of the Deaf community, a Hard of Hearing individual, and NJ residents interested in the welfare of Deaf and Hard of Hearing Children (including a parent of Deaf and Hard of Hearing children and a teacher of the Deaf and Hard of Hearing).

The NJ Stakeholders (NJSH) group, a new HRSA grant initiative, held four meetings this year. The NJSH group is made up of providers who work in the EHDI system and parents of Deaf/Hard of Hearing children, including audiologists, Early Intervention providers, the NJ Part C liaison, Teachers for the Deaf/Hard of Hearing, a cochlear implant provider, case managers, and DOH EHDI staff.

The EHDI Advisory Committee was reconvened with members recruited to represent health care professionals, parents/families of deaf or hard of hearing children, individuals that are deaf or hard of hearing, as well as various state programs. The annual meeting provides an opportunity for members to provide information, build partnerships, share concerns, and offer input to the EHDI Program.

The EHDI program provides 'next steps' letters to pediatricians and families who have a child with a newly diagnosed hearing loss. The next steps letter shares recommended follow up and encourages pediatricians to report those actions to the EHDI program. These letters were edited to be more reader friendly, updated with current family support information, and now include a note to families from a diverse group of trained support parents who have a child with hearing loss.

Annual Report- SPM # 4 Percent of live children registered with the Birth Defects and Autism Reporting System (BDARS) who have been referred to NJ's Special Child Health Services Case Management Unit and who received services.

The Birth Defects and Autism Registry links registered children electronically via an interface with the CMRS system so that they are offered services through our county-based Special Child Health Services CMUs. Case managers are electronically notified when a child has been registered and released for follow-up. Case managers use the CMRS to create and modify ISPs, track services, create a record of each contact with the child's family, create standardized quarterly reports and register previously unregistered children. The annual state performance indicator below has consistently exceeded the annual objective for all the reported years included the table below. While we make good strides to engage children who are referred from the BDAR, not all children with a mandated reportable condition will need case management service. Specifically, children with conditions are corrected at birth such as hypospadias and would not need ongoing supports.

Table SPM # 4: Percent of live children registered with the Birth Defects and Autism Reporting System who have been referred to NJ's Special Child Health Services Case Management Unit and who are receiving services.

	2019	2020	2021	2022	2023
Annual objective	92.2%	92.4%	92.6%	92.8%	93.0%
Annual Indicator SPM #4	96.1%	95.1%	95.9%	95.0%	96.1%
Numerator	12,018	13,473	12,753	14,249	14,884
Denominator	12,501	14,178	13,302	14,999	15,492

\*Data Source- The New jersey Special Child Health Services, Family Centered Care Services; Notes: The numerator reflects all children whose record has any of the five following criteria for services: Case closed within SFY with a reason of "goals achieved," Child referred to Early Intervention within SFY, Individual Services documented with a begin and/or end date within SFY, Individual Service Objectives documented with a perform date within SFY, and Case Management Actions (excluding any letter correspondence that is part of an initial letter series) documented with a date performed within SFY. These children must have received services within a given SFY and registered with the BDARS (registration date not restricted to SFY). The denominator represents the number of children served by SCHSCM in SFY who had been registered with the BDARS regardless of registration date (i.e., the numerator) plus any additional children who were registered and released to case management within a given SFY but did not receive services as currently defined.

BDAR and SCHSCM staff collaborate to improve the system's functionality, ease of use, and efficiency. CMRS allows CMUs to receive registrations in real time, enables faster family contact, and more rapidly assists a registered child gaining access to appropriate health, education and other resources and services. SCHSCM staff perform annual reviews of electronic records in CMRS to assess key functions and expectations of the CMUs and evaluate Individual Service Plans to assess linkage to services. SCHSCM staff continues to review electronic documentation of the six key performance indicators (e.g., medical home, transition to adulthood), with an expectation of refining how this information is collected within CMRS.

Annual Report- SPM # 5 Average age (in years) of initial diagnosis for children with an Autism Spectrum Disorder SPM #5 was chosen to measure the timeliness of diagnosing autism in children. Early diagnosis is important for initiation of services, as children who receive services at an early age have better functional outcomes. While the causes of autism are not known, receiving intensive services early in a child's life can improve development in speech, cognitive, and motor skills. Appropriate diagnosis at an early age is an important precursor to ensuring that families gain access to early and intensive intervention.

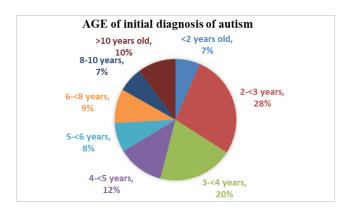
Many factors influence the age at which a child is first diagnosed with autism. The age at which signs of autism are first exhibited or noticed by the family can vary and can be influenced by the family's experience with other children, knowledge about typical developmental milestones, or the types of delays or behavioral differences the child is experiencing. A young child who has more severe symptoms (such as no speech, extreme tantrums, stereotypical behavior, or being unresponsive to social interaction) is likely to be evaluated sooner. Cultural differences and expectations of child behavior can also play a role. Other family members and even primary care providers may advise parents of very young children to take a "wait and see" approach when they raise concerns about atypical development. Even when providers do promptly advise families to seek an evaluation with a specialist, there can be long wait times for appointments.

Table SPM # 5: Average age (in years) of initial diagnosis for children with an autism spectrum disorder

	2017	2018	2019	2020	2021	2022	2023
Annual Indicator SPM #5	5.5	5.1	4.9	5.0	4.8	4.8	5.1

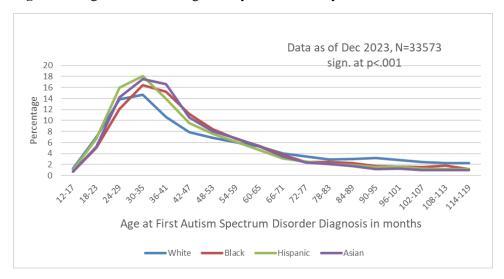
In 2023, there were over 4,000 children diagnosed with autism. The average age of initial autism diagnosis is 5.1 years old. The current average age of 5.1 indicates an increase from the previous five years (2018-2022) when the average ages were approximately 5.0 years. For all the children registered with Autism registry around 7% of children received an initial Autism diagnosis before two years of age. 28% of children were diagnosed two to three years old and 20% were diagnosed three to four years old. 10% of children were diagnosed after 10 years of age.

Figure 20. Age of Autism Diagnosis



While the average age is useful for comparison to other states, age at diagnosis is not normally distributed. As seen in the figure below, however, there are three age periods when children are mostly likely to be diagnosed. The first is between two and three years of age. During this time Black NH and Asian children seem to be diagnosed later than White NH and Hispanic children. The second peak is between four and six years of age. One theory as to why White NH children have a lower peak is because they had been diagnosed between 24 and 29 months or are more likely to be diagnosed at a later time.

Figure 21. Age of Autism Diagnosis by Race/Ethnicity



To ensure the quality of the data, BDARS staff have conducted outreach to educate and inform physicians and health facilities about the Registry, how they can register children with autism living in NJ, and the rules regarding the Registry. Registry staff has visited and trained staff from medical centers specializing in child development, developmental evaluations, and behavioral health. Additionally, they have trained staff from many private pediatric practices that follow older children with autism through annual well visits. Registry staff has also trained several psychiatric/behavioral departments located within hospitals. Staff from the Registry presented information concerning the Autism Registry to state and county case managers as part of training on the case management electronic component of the BDARS. They continue to retrain new staff within health facilities as needed. Staff has also created materials for both providers and families about autism, and these materials have been translated into multiple languages, including Spanish, Korean, Polish, Hindi, and Arabic. There is also information about the Autism Registry on the DOH website, and staff continue to make conference presentations and exhibits.

TVP will continue to address this performance measure by working with the NJ Chapter of the American Academy of Pediatrics and the Elizabeth M. Boggs Center on Developmental Disabilities, NJ's University Centers for Excellence in Developmental Disabilities, in reaching out to various health care providers and distributing information and trainings on the Learn the Signs, Act Early campaign that educates providers on childhood development, including early warning signs of autism and other developmental disorders, as well as to encourage developmental screenings and intervention.

One of the most important BDARS changes this year allows providers to verify if a child had already been registered for another provider. This change significantly reduced the burden on our reporting agencies and improved the system's efficiency; this is significant as our mandate requires all children 0-22 with ASD to be registered. Children see many healthcare providers; each needing to verify registration or register the child. With the new system, healthcare providers can simply search the system for a child, thus, significantly reducing the number of duplicate registrations. Moreover, if a child had been registered with non-autism diagnoses, their providers can now add the new autism diagnosis and review and update the child's contact information. Additionally, the autism data collection pages have been redesigned to provide more check-off options rather than asking providers to use text fields to provide information about comorbidities, symptoms, and other pertinent information.

# Annual Report - NPM #11 Percent of children with and without special health care needs having a medical home)

SCHSCM staff will continue to refine tracking of Performance Measures in CMRS and provide documentation training to case managers to ensure activities related to these measures are accurately counted. CMRS is being redesigned to improve performance on the Six Core Outcomes for CYSHCN and promote targeted improvement to the documentation for access to a medical home (NPM #11) and transition to adulthood (NPM #12). With CDC Surveillance and Expanded Laboratory Capacity (ELC) grant funding, the redesigned system will support tracking of CYSHCN referred to SCHSCM and monitoring of services offered and/or provided to determine family/child outcomes.

Updates continues to be made to CMRS to accommodate reporting, data collection, and tracking of medical home components. Having a primary care physician is the 'first step' in building the infrastructure of a medical home for CYSHCN. ESM #11.1 provides a baseline for programmatic needs to increase the percentage of CYSHCN with a primary care physician and identify the 'next steps' needed to establish medical homes for CYSHCN, a medical home webpage on the Department's website, includes a Shared Plan of Care, a medical home tool for families.

Providing comprehensive care to children in a medical home is the standard of pediatric practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventative care and immunizations. They are also less likely to be hospitalized for preventable conditions and are more likely to be diagnosed early for chronic or disabling conditions. The AAP specifies seven qualities essential to medical home care: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. Ideally, medical home care is delivered within a trusting and collaborative relationship between the child's family and a competent health professional familiar with the child, the family, and the child's health history. The Maternal Child Health Bureau (MCHB) uses the AAP definition of medical home. CMUs continue to link families to medical homes and document within CMRS all seven qualities essential to medical home care.

CYSHCN, with a medical home, has been a priority for the SCHSCM program and has been supported by several partnerships and collaboratives. Having a primary care physician service identified in a child's ISP

developed with a case manager served as a medical home proxy beginning with 2014 reporting. As part of the Medical Home grant, SCHSCM and its partners developed the Shared Plan of Care (SPoC), a document meant to increase care coordination for CYSHCN. This additional component was added to the medical home proxy with 2017 reporting continued today for ESM 11.1. While a medical home is more comprehensive than just having a primary care physician, it is also imperative for a child to have consistent health insurance to increase access to the provider. Of the 16,188 children aged 0 to 18 years served in SFY 2023, 36.6 % had a primary care physician and/or SPoC documented. Of those children, approximately 54% had insurance identified in their ISP, which remains similar to the prior year. The percent of CYSHCN ages 0-18 years served by CMUs with a primary care physician and/or SPoC has been selected as ESM 11.1. The annual state performance indicator below has consistently exceeded the annual objective since 2019: 37.9% vs. 37% in 2019, 40.9% vs. 38% in 2020 and 40.1% vs. 39% in 2021, and 40% vs. 40.6% in 2022. In 2023, SCHSCM saw a reduction, 36.6% vs. 41% due to lack of documentation into the Case Management Referral System. SCHSCM has addressed this documentation issue in CMRS by creating a program policy for case managers requiring annual documentation on medical home in the system.

Table NPM 11 - Percent of children with and without\* special health care needs having a medical home.

	2019	2020	2021	2022	2023
Annual NPM #11 Indicator	37.9%	40.8%	40.1%	40.8%	36.6%
Numerator	6,654	6,503	5,783	6,347	5,928
Denominator	17,542	15,919	14,407	15,619	16,188
Data Provisional or Final	Final	Final	Final	Final	Provisional

\*Note: Data above reflects CYSHCN ages 0-18 years served by Special Child Health Services Case Management Units with a primary care physician and/or Shared Plan of Care.

Data Source - The New Jersey Special Child Health Services, Family Centered Care Services

While SCHSCM data only include children with special health care needs who live in NJ and participate in our case management system, our findings are not different from those of the National Survey of Children's Health (NSCH). NSCH estimates the percentage of children (0-17) with special health care needs having a medical home (NPM 11) for the combined years of 2010-2021 is 40.4% (n=349) For the single year (2022), 36% (n=157) are estimated to have a medical home.

For many CYSHCNs, a specialty provider often serves as the child's usual source of care, where care coordination becomes vital to ensure primary care services are not overlooked. Past chart reviews have shown that greater than 90% of CYSHCN receiving services through SPSP grant-funded programs have a primary care physician listed. In SFY20, the program included evaluating every child seen in a SPSP grant-funded program for the designation of a primary care provider as part of the grantee's goals and objectives. The Title V CMUs and pediatric specialty providers will continue to provide a safety net for families of CYSHCN.

Annual Report - NPM #12 (Transition to adulthood)

The transition of youth to adulthood has become a priority nationwide, as evidenced by the clinical report and algorithm developed jointly by the AAP and the American College of Physicians to improve healthcare transitions for all youth and families. Over 90% of children with special health care needs now live to adulthood but are less likely than their non-disabled peers to complete high school, attend college, or be employed. Health and health care are cited as two of the major barriers to making successful transitions. Adolescence is a period of major physical, psychological, and social development. As adolescents move from childhood to adulthood, if able, they assume individual responsibility for health habits, and those who have chronic health problems take on a greater role in managing those conditions. Receiving health care services, including annual adolescent preventive well visits, helps adolescents adopt or maintain healthy habits and behaviors, avoid health-damaging behaviors, manage chronic conditions, and prevent disease.

The New Jersey Special Child Health Services Case Management Units provide children and youth with special health care needs with transition to adulthood services up until their 22nd birthday. Data for transition services provided by SFY is presented below. The annual state performance indicator consistently exceeded our annual objective for all reported years included in the table below except 2023 due to incomplete reporting; (45.2% vs. 44% in 2019, 43.6% vs. 37% in 2020, 45.0% vs. 40% in 2021, 47.4 vs. 43% in 2022) and 42.5% vs.46%. The redesign of CMRS will greatly expand the ability to track specific transition services. A current limitation of the data system is that transition exists as a single service to be recorded on an ISP, however the redesign will make transition its own service domain, allowing case managers a greater depth of detailed data to be easily recorded and readily obtainable for data analysis, reporting and evaluation. For 2022, the National Children's Heath Survey estimates that 26.5% (n=68) of adolescents with special health care needs, ages 12 through 17, received services necessary to make transitions to adult health care in NJ. For the pooled years of 2020-2021, the National Children's Heath Survey estimates that 13.4% (n=177) of adolescents with special health care needs, ages 12 through 17, received services necessary to make transitions to adult health care in NJ. While CMUs provide no cost resources and referral services, many children may receive these services through their school; therefore, these two measures are not equivalent.

Table: Provision of Transition Service in New Jersey for children with special health care needs ages 12 to 17 years.

	2019	2020	2021	2022	2023
Annual NPM #12 Indicator	45.2%	43.6%	45.0%	47.4%	42.5%
Numerator	1,642	1,102	955	962	808
Denominator	3,635	2,530	2,125	2,030	1,900
Data Provisional/Final	Final	Final	Final	Final	Provisional

Data Source - The New Jersey Special Child Health Services, Family Centered Care Services Note: CMUs serve children with special health care needs until their 22nd birthday. The 2023 denominator is provisional as data validation is completed for the reporting year.

Children aged 12-21 are offered and/or provided with transition services. These data are not shown in the table above. Seven possible types of transition to adulthood services were identified as proxies; the identification of an adult-level primary care physician; transition-specific services; employment; health

insurance; Supplemental Security Income; SPoC; Exceptional Events documented in the youth's record tied to transition.

Identification and monitoring of transition to adulthood for CYSHCN and their families served through the CMUs statewide is ongoing. Transition packets continue to be updated, shared, and thoroughly reviewed with families, and linkage to community-based support is provided. State staff monitors the CMUs efforts to outreach to CYSHCN regarding transition, including documentation of goals related to transition on the ISP.

The CMUs continue to facilitate transition to adulthood with youth by ensuring a transition to adulthood goal on the ISP. Likewise, exploring youth and their family's needs to ease the transition with insurance, education, employment, and housing, while linking them to community-based partners will continue.

Ongoing CMRS presentations to the case managers stimulate active discussions about how SCHSCM documentation in the system relates to our CQI efforts and MCH Title V Block Grant reporting. These presentations also inform CMUs on areas for training to ensure consistent documentation methods, shifting from a lengthy narrative charting style to drop-down menus supported by brief entries that use shorter and more consistent terminology. Monthly meetings are held jointly with SCHSCM state staff and all 21 CMUs to provide additional CQI presentations highlighting progress and additional areas of improvement in documentation on the core Title V and State performance measures.

CMUs and pediatric specialty providers will refer youth and/or their families to the NJ Council for Developmental Disabilities for participation in Partners in Policymaking (PIP) self-advocacy training, as well as continue to assist youth and their families in advocating for transitional supports through their Individualized Education Plans and community-based supports. TVP will continue to participate in PIP mock trials to facilitate the development of clients' self-advocacy skills.

CMUs largely noted documentation of transition planning to occur on or about age 14. A discussion with families/youth about transition planning and the distribution of transition packets are documented in CMRS. An anecdotal observation by the case managers noted that families prefer to receive materials incrementally, rather than in one large packet filled with resources. That incremental method provides them with the opportunity to focus on one, or a few transition needs at a time, such as primary care provider, access to Supplemental Security Income, and/or health insurance, including Medicaid, Medicaid expansion, and/or private insurance or the Marketplace; education/job training supports; statewide systems of care including the Department of Human Services Division of Developmental Disabilities and/or the DCF's Children's System of Care Initiative, and others.

Through an agreement with SPAN, the Family WRAP (Wisdom, Resources, and Parent to Parent) project provides information, resources, and one-to-one family support that are directly helpful to clients active in SCHSCM and case managers.

Due to the rising percentage of children in NJ diagnosed with Autism Spectrum Disorder, SCHSCM partnered with Autism New Jersey to provide support to case managers for children active in SCHSCM who have been diagnosed with ASD as well as other learning disabilities. This agreement enables case managers to provide the necessary support to children and their families active in SCHSCM.

Linkages developed through current and previous ISG grants have facilitated the distribution of materials developed by SPAN, NJ AAP, Autism NJ, NJDOH, and other community partners engaged in the

Community of Care Consortium to medical practices. Community-based partners continue to identify resources and linkages to support transition to adulthood for CYSHCN.

DCF's Children's System of Care program works collaboratively with the DOE Offices of Special Education, the DDD, and the DVRS to help facilitate transition to adulthood services. Transition to adulthood begins in CMU at 12 years old. After age of 21, eligible young adults are provided developmental disability services by the DDD. Training on these systems for adolescents with developmental disabilities is occurring regularly among the CMUs. Collaboration with intergovernmental and community partners, including Autism NJ, DDD, DCF, NJ Council on Developmental Disabilities, Boggs Center, SPAN, the Arc, Traumatic Brain Injury Association, and families, is critical to access appropriate services and supports. Identification and monitoring of transition to adulthood needs for CYSHCN and their families served through CMUs statewide are also in process. County-specific transition packets, including resources related to education, post-secondary education, vocational rehabilitation, housing, guardianship, SSI, insurance, and Medicaid/NJ Family Care, are shared with families, and linkage with community-based support is provided. State staff monitor the CMU's efforts to outreach to CYSHCN regarding the documentation of transition goals related to adolescents' service plans.

The adolescent subset of CYSHCN served through the Title V Program remained relatively the same between SFY 2022 and SFY 2023. In SFY23, 16% of patients seen at the CECs and 15% of CYSHCN of the same age group were served at Cleft Lip Cleft Palate-Craniofacial Centers. In addition, youth between the ages of 14 and 18 comprised 27% of those served at PTC Centers. The SPSP providers engage with adolescents and their families to facilitate transition to adult services. Transition services primarily include discussions about the importance of adult care, options for adult care (providers/locations), sharing resources regarding genetics, family medicine, adult providers, support groups, and other medical and social-related needs. The linkage of CYSHCN to multidisciplinary team members, including social work and other community-based systems such as SCHSCM, SPAN, and disability-specific organizations, including the Arc, Tourette's Association, and Parents' Caucus, are strategies implemented by the SPSP agencies. As shown in past reviews and surveys, SPoC, and documentation on transition to adult care vary amongst the three SPSP categories: CEC, Cleft Lip Cleft Palate-Craniofacial centers, and PTC centers. The SPSP collaborates with each grantee to ensure that a definition of transition to adult care is established at each site and that practice policies regarding transition to adult health care are created and implemented.

Aligned with the Title V Program and the program funded by Part D of the Ryan White Care Act, the NJ Statewide Family Centered HIV Care Network remains a leading force in providing care to women, infants, children, youth and families infected and affected by HIV disease in the State. Consequently, there is ongoing collaboration across systems within the Division of Family Health Services' Maternal Child Health and CYSHCN's programs and the Ryan White Part D program to support women, infants, children and youth's needs in the community. This collaboration cultivates trust between family-serving entities in the case that additional resources are needed. NJ ranks third in the nation for pediatric cases. Of youth 13-24 years, 177 were living with HIV/AIDS, and of children 0-12 years, 25 were living with HIV/AIDS in 2023. Through diligent efforts to treat and educate HIV-infected pregnant women, the perinatal transmission rate in NJ remains very low. Intensive case management and appropriate antiretroviral therapy enable children with HIV to survive and successfully transition into adulthood.

Children with Special Health Care Needs---Application year

Plan for the Applicant Year - NPM #11 (Percent of children with and without special health care needs having a medical home)

State Special Child Health Services staff will continue to refine tracking of Performance Measures in our Case Management Referral System (CMRS) and provide documentation training to case management units to ensure activities related to these measures are accurately counted. CMRS is being redesigned to improve performance on the Six Core Outcomes for CYSHCN and promote targeted improvement to the documentation for access to a medical home (NPM #11) and transition to adulthood (NPM #12). With CDC Surveillance and Expanded Laboratory Capacity (ELC) grant funding, the redesigned system will support tracking of CYSHCN referred to SCHSCM and monitoring of services offered and/or provided to determine family/child outcomes.

Updates are being made to CMRS to accommodate reporting, data collection, and tracking of medical home components. Having a primary care physician is the 'first step' in building the infrastructure of a medical home for CYSHCN. ESM #11.1 provides a baseline for programmatic needs to increase the percentage of CYSHCN with a primary care physician and identify the 'next steps' needed to establish medical homes for CYSHCN, a medical home webpage on the Department's website, includes a SPoC, a medical home tool for families).

### Plan for the Applicant Year - NPM #12 (Transition to adulthood)

Efforts to improve documentation of transition to adulthood activities performed by case managers and documented in CMRS will continue. State staff provide ongoing technical assistance and guidance via site visits, desktop audits, and conference calls to improve the data collected and reported on transition to adulthood activities and client outcomes.

Transitioning to an adult program for CYSCHN is a critical decision that must be planned appropriately to ensure continuity of care. Although TVP will continue to assess youth's progress toward transition and linkage with community-based supports, the SCHSCM and SPSP programs are exploring the development of standardized needs assessment and quality indicators to better measure NJ CYSHCN's experiences. An example of a quality indicator is the acuity tool that is being built into the electronic database; this will assist case managers in highlighting children on the cusp of adolescence and adulthood. The acuity tool identifies and scores the child's and family needs in different domains including Healthcare/Medical Needs, Growth and Development, Insurance coverage, Adaptive Equipment & Accessibility, Coordination, Communication, Language, Educational / Vocational needs and attainment, Transition service needs, use of Community Resources and Financial/Food Insecurity / Housing Stability. For NPM 12, needing to address the transition to adulthood is imperative for the child's subsequent success in adulthood.

The FCCS program is currently undergoing a comprehensive redesign of CMRS that will greatly expand the ability to track specific transition services. A current limitation of the data system is that transition exists as a single service to be recorded on an ISP (individual service plan), but the redesign will make transition its own service category, allowing case managers a greater depth of detailed data to be easily recorded and readily obtainable for data analysis, reporting and evaluation. The redesign will allow

documentation of Transition Services by service domains including education, vocational training, employment, financial, social support, housing and healthcare.

SPM # 3 Percentage of newborns who are discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening, and who have outpatient audiological follow-up documented.

An important SPM in the domain of CYSHCN is SPM #3 (Percentage of newborns discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening, and have outpatient audiological follow-up documented) was selected during the last Five-Year Needs Assessment.

The EHDI program will continue using HRSA EDHI funding for county-based special child health services case managers to conduct follow-up phone calls to parents and physicians of children needing hearing follow-ups. The EHDI Program also sends hospital-level surveillance data to NJ birthing hospitals. Monthly hospital contacts continue to receive a reconciliation list of children that are still in need of follow-up after missed or referred inpatient hearing screening, as this has been shown to improve successful follow-up rates. A report with each birthing hospital's overall statistics is sent annually. The program will continue to distribute the audiology facility reports to highlight the timeliness of follow-up and identify children with incomplete follow-up testing.

The EHDI program plans to continue working with medical homes to ensure that children receive timely and appropriate follow-up after a referred hearing screening or inconclusive follow-up testing. An extract available in the NJIIS allows the EHDI program to identify the name, address, and fax number of the medical home provider that has most recently provided immunization data for a child and will use this information to send fax-back forms to provider offices to remind them to refer children for additional follow-up as needed.

The program will continue the grant-supported activities, including case management outreach to families in need of hearing follow-up and support by the EI Hearing Consultants. In addition, the HRSA EHDI grant-supported Deaf and Hard of Hearing Mentoring and Role Model program for families of children identified with hearing loss has been operational since 2018.

EHDI staff will continue educational presentations to hospital staff, pediatricians, audiologists, Special Child Health Service Case Managers, Early Intervention Service Coordinators, and other healthcare professionals, focusing on decreasing the number of lost children to follow-up. The EHDI program frequently uses online meeting platforms to make educational outreach efforts more accessible to the target audiences, reduce staff travel time, and improve efficiency while decreasing costs. NJ EHDI staff will continue to collaborate with the EI Hearing Consultants to coordinate outreach meetings with pediatric audiologists regarding timely referral of children with hearing loss to Early Intervention. As per the suggestion of the NJ EHDI advisory board, The Hearing Evaluation Council, regarding CMV/pediatric hearing loss awareness/prevention, NJ EHDI has updated its website with public service information in multiple languages geared toward women of childbearing age.

New Jersey law (1/18/22, P.L.2021, c.413) requires all infants born in our state to be screened for congenital Cytomegalovirus (cCMV). This legislation also requires the establishment of a public awareness campaign to educate New Jerseyans on the value of early detection, intervention, and treatment options for children diagnosed with this condition. cCMV is the most common congenital infection in the United States, with approximately 1 in 200 children born with this condition or approximately 30,000 children born yearly. According to the CDC, 10–20% of children born with cCMV will go on to have

neurodevelopmental disabilities, including sensorineural hearing loss. Every year, as many as 400 infants die because of this virus.

An ad hoc committee that includes a diverse group of healthcare professionals and NJ DOH staff who share an interest in this topic has been meeting regularly to investigate evidence-based universal cCMV screening protocols and formulate follow-up guidelines for those children in New Jersey who have tested positive for this diagnosis.

Committee members include representatives from two primary advisory groups that serve the NJ DOH: The Newborn Screening Advisory Review Committee and the Hearing Evaluation Council for the New Jersey Early Hearing Detection and Intervention Program. Currently, the committee is developing condition readiness criteria for New Jersey's Newborn Screening Panel will be presented at the May 2024 meeting. In addition to surveying State birthing facilities regarding cCMV screening practices, the NJ DOH is also participating in a national survey from the CDC regarding cCMV surveillance activities in our state.

SPM # 4 Percent of live children registered with the Birth Defects and Autism Reporting System who have been referred to NJ's Special Child Health Services Case Management Unit and are receiving services.

SPM #4 was chosen to improve the timeliness and effectiveness of the BDARS, which has been an invaluable tool for surveillance, needs assessment, service planning, research, and linking families to services. Through CDC funding, the BDARS continues to be upgraded and improved. In the past, these upgrades have included creating the Pulse Oximetry and Exceptional Events modules and improving functionally to decrease the burden on providers and state staff from unnecessary duplications.

BDARS staff will continue to provide training, on an as-needed basis, to birthing facilities, autism centers, audiologists, and other agencies to use the revised electronic BDARS and its modules. Staff will continue to monitor the use of the electronic BDARS and will assist reporting agencies with concerns. In addition, BDARS staff will continue to review the quality of the data in the BDARS and its modules.

On-site visits will be conducted at each CMU to ensure proper usage of the CMRS as needed and to strengthen the relations with FCCS SCHSCM staff; this will allow more consistent use of the system linking referred families to services. SCHSCM staff provide ongoing feedback and technical assistance to CMUs on a statewide, county-level, and individual-level basis.

FCCS SCHSCM will continue to enhance the CMRS system by adding new measures to capture needs, improving case definition across our case management units, and enhancing the system's exceptional events module so communication with families can be streamlined and improved in times of emergencies. The way in which cases are defined as "active" or "inactive" impacts the ability to appropriately measure such things as length of services and number of children being serviced. State SCHSCM staff have been working intensively to standardize the CMUs definitions and will be working with the programmers to ensure the system is accurately capturing data; this will allow the CMUs the flexibility they need to better document the services provided to their families and yield accurate quarterly and annual reports.

SCHS/FCCS SCHSCM has been provided CDC-Enhancing Laboratory Capacity funding to redesign the CMRS system. The improvements will allow for an integrated documentation model to incorporate not only service provisions, but changes in need resulting from exceptional events that are cataloged appropriately and chronologically. In the wake of the COVID-19 pandemic, the increased need to gather

details surrounding exceptional events was apparent. An exceptional event creates and documents the unique needs of the CYSHCN population that the CMUs serve. This redesign will allow for documented emergency preparedness and anticipation of unique needs for this vulnerable population during these extraordinary events. Examples of other exceptional events outside of natural disasters and statewide emergencies are more intimate family-centered issues such as the change of family structure/health (e.g., death of an immediate family member, divorce, unforeseen illness/injury), housing issues (e.g., loss of housing), economic factors, changes in insurance status, or new diagnoses. With improved data capture regarding exceptional events, the program will be able to develop emergency preparedness plans and directed assessments to serve the child's/family's needs more effectively. In addition to the exceptional events module, the CMRS redesign will provide additional insights, improve functionality, and increase data capture in the ISP module.

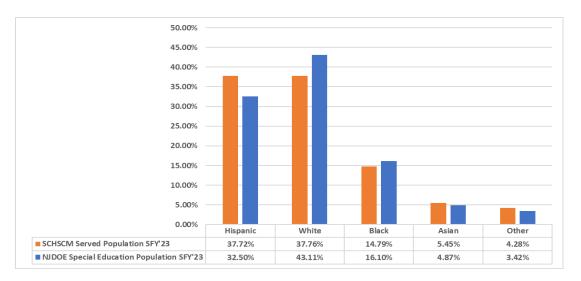
SCHSCM staff will further examine the population they serve and how they can establish quality improvement and quality assurance measures for maintaining an improved and uniform practice of case management, developing policies and procedures, and monitoring equitable services across the population. The main priorities of this redesign are to improve the quality of data reporting, improve the user experience, and implement an acuity measurement. The redesign will allow for enhanced reporting regarding medical homes for the CYSHCN population and improved data quality surrounding the transition to adulthood process for the adolescent population served by SCHSCM. SCHSCM will use a weighted scale that utilizes pivotal information in CMRS, such as diagnosis, linkage to services, insurance information, medical home, transition to adulthood, and other key data points, to determine each child's acuity level in a format that the end users easily understand. These data will also allow SCHSCM staff to evaluate staffing of CMUs, identify communities of greater need, and determine each child's real-time level of need at-a-glance.

Early stages of this redesign included exploration of data systems used by Title V CYSHCN case management programs in other states. Direct communications with some of these programs provided useful feedback in developing a framework for NJ to build upon for developing the requirements for this redesign. The SCHSCM team continues to collaborate with the system developer to ensure that the system requirements are met to help them achieve the goals noted above.

Occurring in tandem with the CMRS redesign, SCHSCM will continue creating and revising policies and procedures to create a more uniform standard of practice for case management services and consistent documentation in a child's record across the state. These innovations will enhance statewide monitoring and aid the CMUs in providing comprehensive and equitable care in every county.

To monitor equitable services, SCHSCM staff has begun exploring Race/Ethnicity data on the population served in SCHSCM to ensure the program reaches all communities within New Jersey. Below is a graphic comparing the SCHSCM population served in SFY23 by Race/Ethnicity Compared to Race/Ethnicity of NJ Department of Education Special Education students which indicates that SCHSCM is reaching diverse communities throughout New Jersey. In the coming year, SCHSCM staff will be working to disaggregate categories to examine better who utilizes CMUs and where there is a need for more outreach to ensure that all children with special health care needs and families may benefit from SCHSCM services.

**Figure 22.** Race/Ethnicity Data for SCHSCM Served Population SFY23 vs. New Jersey Department of Education, Office of Special Education SFY'23



Data Source: NJ DOE, Office of Special Education Programs, SFY'23 (Ages 3-21 Only)

Data Note: "Other" category is defined as the combination of "Two or More Races," "American Indian or Alaskan Native," "Native Hawaiian or Pacific Islander," and "Other Race."

In FY25, SCHS is piloting a new way to address the emerging needs of families with children with Autism who have severe and challenging behavior under the age of seven. SCHSCM is collaborating with Autism NJ (ANJ) to implement a Statewide Intensive Case Manager. This project will onboard an Intensive Care Case Manager who will work with the CMUs to identify children for risk factors of severe challenging behavior based on inclusion criteria developed with AutismNJ. Once identified, these families will be followed by the Intensive Care Case Manager. This specialized case manager will conduct a comprehensive service review and engage with the family, treatment providers, and ANJ to create an individualized plan. In preliminary analysis, SCHSCM estimated 900 children, age 6 and under, met the initial criteria to participate in the pilot project. The goal of the project is to provide families with additional strategies, programs, and education to decrease the likelihood of severe and challenging behaviors.

### SPM # 5 Average age of initial diagnosis for children with an autism spectrum disorder.

NJDOH will continue to address this performance measure by working with the NJ Chapter of the American Academy of Pediatrics and the Elizabeth M. Boggs Center on Developmental Disabilities, NJ's University Centers for Excellence in Developmental Disabilities, in reaching out to various healthcare providers and distributing information and trainings on the Learn the Signs, Act Early campaign. This initiative educates providers on childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screenings and intervention. In addition, the Governor's Council for Medical Research and Treatment of Autism has funded additional clinical centers in their pursuit to create a NJ Autism Center of Excellence.

Additionally, The Autism Detection + Connection + Intervention (DCI) Project, led by the Rutgers Children's Research Center at NJ Medical School, is a groundbreaking initiative designed to enhance early identification and intervention for autism spectrum disorders (ASD) among children aged 18-36 months. The project leverages a robust partnership including Rutgers' Early Intervention Program, WIC Program, Pediatric Continuity Clinic at University Hospital, SPAN, and Youth Consultation Services, with Rutgers Children's Research Center leading and coordinating the effort.

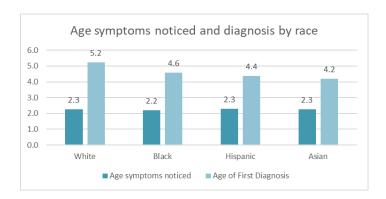
The project operates in three phases: Detection, Connection, and Intervention. In the Detection phase, an effective ASD screening tool, the Psychological Development Questionnaire for Toddlers (PDQ-1), is utilized to identify at-risk children. This phase aims to lower the average age of ASD diagnosis, which has remained around 52 months despite increased awareness and diagnostic capabilities. Following detection, the Connection phase involves SPAN peer counselors—parents of children with disabilities—who offer guidance and support to the families of at-risk children. This peer support is needed in navigating the path to obtaining diagnostic and early intervention services, addressing potential barriers such as language, culture, and stigma. Finally, the Intervention phase involves direct services provided by Youth Consultation Service (YCS), including diagnostic evaluations and interventions like DIRFloortime® to support the child's development.

The DCI project was initiated in July 2023 and has already shown promising results in its pilot phase, significantly improving the rates of autism screening, and ensuring earlier diagnostic evaluations and interventions. The long-term objectives of the project include expanding the program to additional locations, enhancing diagnostic capacities, and establishing universal ASD screening as a standard of care. This project not only aims to reduce disparities in the timely diagnosis of ASD but also enhances overall family engagement, ensuring that all children have the best start possible.

In the upcoming year, Autism Registry staff will continue to perform in-depth analyses of the registry data and merge with other data sets to better understand the needs of those with autism. As indicated above, the average of initial diagnosis is 4.8 years. The criteria for a diagnosis of autism are deficits in a person's social communication and interaction, restrictive or repetitive behaviors, interests or actions that become apparent in early childhood and create functional limitations or impairment in everyday life. The severity is further classified from levels 1 to 3, indicating the support the person needs (requiring some support - level 1, substantial support - level 2, and very substantial support - level 3). Because the registry collects the individual's symptoms at the time of diagnosis, and doesn't track changes over time, younger children may go on to exhibit additional symptoms that were not observed or not recorded in the child's registration. Of particular concern are behavior that put the child at risk for injuries, inability to remain safely in the home, or even death. Using hospital Uniform Billing data, the registry will compare the number of hospitalizations of people with autism associated with events such as crises due to comorbid mental health conditions, self-injury, and accidents, including those that occurred due to the person eloping (for example, leaving the home and wandering, near-drowning incidents, and darting into traffic). This analysis will provide a better understanding of the level of intensive needs within our families with children who have autism.

In addition, ascertaining racial and ethnic diversity beyond currently used categories is of interest to the registry and important in understanding differences in the average age of autism diagnosis by race/ethnicity (Figure 23). Cultural norms may impact what is considered typical childhood behavior and provide insight into the differences in age of diagnosis or even whether a child is evaluated for autism at all. A planned paper should help us signal that one's culture may be a social determinant in seeking medical care among families with children with an autism spectrum disorder. The registry will utilize UB data to expand beyond current racial categories and provide more information about the diversity of the population.

Figure 23. Age symptoms noticed and diagnosis by race/ethnicity.



## Cross-Cutting Systems Building – Annual Report

This section concerning the domain of Life Course includes the SPN #8 Improving Integration of Information Systems and the NPM #13 Oral Health. ESM 13.1 for oral Preventive and dental services for children enrolled in Medicaid or CHIP (CMS-416).

### Annual Report - NPM #13:

- A. Percent of women who had a dental visit during pregnancy and
- B. Percent of children, ages 1 through 17, who had a preventive dental visit in the past year

Health cannot be achieved without good oral health. According to the Centers for Disease Control and Prevention (CDC), oral health affects our ability to eat, speak, smile, and show emotions. Oral health also affects a person's self-esteem, school performance, and attendance at work or school. Oral diseases—which range from cavities and gum disease to oral cancer—cause pain and disability for millions of Americans and cost taxpayers billions of dollars each year. Additionally, oral health care remains the greatest unmet health need for children. To address this problem, the National Performance Measure 13 focuses on improving oral Health (NPM 13) for some of the most vulnerable populations, i.e., pregnant women, children and, adolescents.

### 13.1: Percent of women who had a preventive dental visit during pregnancy

# 13.2: Percent of children and adolescents, ages 1 through 17, who had a preventive dental visit in the past year.

Since the 1980s, the New Jersey Children's Oral Health Program (COHP) has provided age-appropriate and developmentally targeted oral health education programs to school-age children covering all 21 counties in New Jersey. In addition, COHP offers oral health education programs, including a newsletter for parenting and community groups for women and infant children. School and community presentations are conducted in areas of high risk for dental disease and high need of oral health services by registered dental professionals, who provide evidence-based oral health and hygiene information, including the oral disease process, tooth anatomy, healthy food choices, reducing the use of sugary foods and beverages, tobacco cessation and the dangers of vape and e-cigarette products, positive lifestyle choices to increase health and reduce systemic disease, and oral injury prevention education. Additionally, all children and families participating in COHP education and outreach programs received free oral health personal care items, including toothbrushes and floss. Currently, schools and community groups have the option of inperson, virtual recorded, and virtual live oral health education, increasing flexibility and access.

#### Some of the COHP achievements in 2023 includes:

- Continued providing Fluoride Varnish application to 838 children to prevent tooth decay.
- Offered oral health literacy/education/promotion programs to over 35,000 school-aged children throughout New Jersey, 1390 of whom had special health care needs.
- Relaunched nutritious food delivery to low-income families and their children and educate them on the importance of eating nutritious food and its connection to oral health.
- Provided oral-health-related nutritional counseling to 2,178 low-income children and adolescents to encourage behavioral change and increase the intake of healthy food choices to improve oral health and general well-being. This project also led to the placement of 10,311 dental sealants in school-aged children.
- Launched New Jersey's second Basic Screening Survey, targeted at the Head Start population (3-5 years old), a nationally recognized dental survey to collect oral health data. In 2022, New Jersey launched its first-ever Basic Screening Survey for third-grade students and submitted the result to CDC.
- Offered training and educational resources to over 35 school nurses in Tendon School district to
  provide health education and evidence-based interventions in school outreach programs for the
  students.

Every two years, the New Jersey Department of Health directs the COHP to survey all State Health Officers and Dental Directors to update the Dental Clinic Directory, "Dial a Smile." This directory, available online on the Department of Health website, serves as a public resource to identify providers of sliding scale, low-cost, and no-cost clinical dental services, increase access to care, and assist the public in establishing dental homes and decrease Emergency Room visits for dental emergencies. Information about the "Dial A Smile" directory and how to find it online is regularly given to community stakeholders and included in COHP special initiatives, programs, and newsletters. The directory was updated in January 2024, and is currently in the final stages of review before being made publicly available.

As the significant body of research points to the relationship between oral health and birth outcomes, the New Jersey Department of Health submitted a new grant application. It proposed to implement a medicaldental integration program between the NJDOH's Oral Health Services Unit and Maternal and Child Health, collaborating with practitioners within the obstetrics and gynecology community throughout the State, with a focus on developing policy, systems, and environmental changes that will lead to more expansive oral health screenings of pregnant individuals and appropriate dental services, as applicable. NJDOH, if funded, would also implement demonstration projects to deliver integrated oral health services within primary care settings for pregnant individuals within two communities and six clinical settings where particularly vulnerable pregnant individuals access medical services in New Jersey. Trenton and Newark, New Jersey, are communities that have significantly high numbers of vulnerable pregnant individuals and, due to shortages of adequate dental providers, present a challenge to these individuals gaining access to effective preventive oral health services, as well as restorative care, where needed. This effort, if funded, will ensure that New Jersey is better positioned to achieve the joint goals of improving oral and maternal health outcomes, including reducing dental caries, bacterial load, chronic disease among pregnant individuals, and preterm birth and otherwise improving the overall health of pregnant individuals in New Jersey. This demonstration project will significantly increase the number of pregnant women who have a dental visit during pregnancy and improve the health outcomes during and postpregnancy for expecting mothers and unborn children.

According to data from NJ FamilyCare (Medicaid) from July 1, 2022 - June 30, 2023, 86,021 pregnant women were served, but during that same period, only 24,919 (29%) of pregnant women accessed any dental services and 17,702 (20%) received preventive dental services.

Cross-Cutting Systems Building-Application Year

Since the 1980s, the Children's Oral Health Program (COHP) has educated the public about the importance of preventive oral health services and good oral health, with programs predominately targeted to school-aged children and pregnant women. With ongoing funding from the HRSA, the New Jersey Department of Health will continue to direct the activities of several programs to address two public health priorities. COHP will continue its outreach, education, and preventive oral health services to children and adolescents throughout New Jersey. COHP aims to expand its oral health training for professionals working directly with the pregnant population, such as training doulas and WIC staff. Additionally, the State Dental Director and State Dental Hygienist will continue to provide technical assistance, serve on multiple committees as subject matter experts, and advocate for the oral health of all New Jersey residents.

Our first Basic Screening Survey (BSS) for third-grade students in 2022 indicated that the burden of oral health diseases in New Jersey children is significantly higher than the national average.

- 36% have untreated decay (national average 20%)
- only 29% have dental sealants (national average 42%)
- 15% need urgent dental care now = 13,200 students have active tooth decay and experience pain To address this significant gap, the Oral Health Services Unit continues its second-year grant activities focused on expanding the dental sealant programs as one of the most compelling evidence-based practices for low-income children and provide nutritional counseling to this at-risk population to reduce the intake of sugary products that increase the incidence of tooth decays.

NJ FamilyCare is the state's Medicaid program, and it has adopted very favorable policies that will help ensure that pregnant residents have access to comprehensive oral health services throughout the term of this demonstration project. First, New Jersey adopted Medicaid expansion through the Affordable Care Act on January 1, 2014. Through the NJ FamilyCare program, covered individuals receive comprehensive oral health services. In 2021, New Jersey expanded its state-funded Supplemental Prenatal and Contraceptive Program to ensure that undocumented women receive necessary prenatal care services. Finally, in January 2023, NJ FamilyCare began covering all youth under the age of 19 in the state, irrespective of immigration status, with incomes at or below 355% of the federal poverty level through Cover All Kids. This program extends to eligible youth with comprehensive medical and dental benefits.

Nearly 1/3 of all births in New Jersey are covered by our State Medicaid program, NJ FamilyCare (35,572 out of 99,346 births in New Jersey from July 1, 2022 – June 30, 2023). Additionally, 86,021 pregnant individuals received services through NJ FamilyCare. However, only 24,919 of those individuals (28%) accessed dental services, and only 17,702 (20%) accessed preventive oral health services during the same timeframe. Additionally, there were 3,336 pre-term births among patients covered by NJ FamilyCare, and 2,417 of these individuals (72%) had not received NJ FamilyCare-covered dental services during their pregnancies. The data confirms the available evidence on the direct correlation between poor oral health and sub-optimal pregnancy outcomes, including pre-term labor and maternal morbidity in connection with childbirth. To address maternal oral health problems, the New

Jersey Department of Health (NJDOH) submitted a new MCH grant application to create a medical-dental integration program between the NJDOH's Oral Health Services Unit and Maternal and Child Health collaborating with practitioners within the obstetrics and gynecology community throughout the State, with a focus on developing policy, systems, and environmental changes that will lead to more expansive oral health screenings of pregnant individuals and appropriate dental services, as applicable. NJDOH, if funded, would also implement demonstration projects to deliver integrated oral health services within primary care settings for pregnant individuals within two communities and six clinical settings where particularly vulnerable pregnant individuals access medical services in New Jersey. NJDOH plans to conduct the BSS for pregnant individuals as the third BSS, followed by the BSS for third graders and Head Start populations. The survey findings will be publicly shared as a valuable resource for all oral health advocates and stakeholders.

NJDOH has added the following four new dental survey questions to the New Jersey Behavioral Risk Factor Surveillance System (BRFSS), which allows a better understanding of the oral health landscape in New Jersey and future planning to meet the needs of the NJ population.

- Q1. Including all types of dentists, such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists, have you visited a dentist or a dental clinic for any reason within the past year?
- Q2. What is the main reason you have not visited the dentist in the past year?
- Q3. How long has it been since you had your teeth cleaned by a dentist or dental hygienist?
- Q4. During the past 12 months have you ever gone to an emergency room for tooth pain because you could not get a dental appointment (or do not have dental home/office to go to on regular basis)?

#### **III.F. Public Input**

Before submission of the Title V application, a period for public comment will be open for all NJ residents who would like to review the application and offer substantive feedback. We expect this open feedback period to begin in June, with a four-week timeline for feedback.

#### **III.G.** Technical Assistance

For this FY, NJ TVP has yet to identify any potential areas in which technical assistance is needed as we work to implement their five-year Action Plan. Should TVP identify any areas that require technical assistance in the upcoming FY, TVP will complete and submit a Technical Assistance Request Form to receive MCHB-supported technical assistance.

#### IV. Title V-Medicaid IAA/MOU

# V. Attachments

## State Action Plan Table

III.D. Five-Year State Action Plan
III.D.1. Five-Year State Action Plan Table

New Jersey		State	Action Plan Table	20	025 Application/2023 Annual Report
Priority Needs	Strategies	Objectives	National and State Performance Measures	Evidence-Based or —Informed Strategy Measures	National and State Outcome Measures
Women/ Maternal He	alth				
Increasing Healthy Births & Reducing Black Maternal and Infant Mortality	Promote evidence-based strategies to increase preventive medical visits for women (ages 18 – 44 yrs.) such as the <u>Community</u> Health Worker model through the Healthy Women, Healthy Families Initiative, and the Matemal, Infant, and Early Childhood Home Visiting Program.	Increase the percentage of women, ages 18 to 44, with a preventive medical visit in the past year by 1% by 2025 (Baseline 2020. BRFSS: 78.7%).	NPM 1: Percent of women, ages 18 through 44, with a preventive medical visit in the past year	ESM 1.1: Percentage of women aged 18-44 who report receiving preventive medical visit in the past year	NOM 2: Rate of severe maternal morbidity per 10,000 delivery hospitalizations  NOM 3: Maternal mortality rate per 100,000 live births  NOM 4: Percent of low-birth-weight deliveries (<2.500 grams)
	Visiting Fregram.	514 66. 16.116).			NOM 5: Percent of preterm births (<37 weeks)
	Continue to cultivate relationships with community and child/health providers and agencies to expand the reach of the initiatives.				NOM 6: Percent of early term births
					(37, 38 weeks)
					NOM 8: Perinatal mortality rate per
					1,000 live births plus fetal deaths
					NOM 9.1: Infant mortality rate per 1,00 live births
					NOM 9.2: Neonatal mortality rate per 1,000 live births
					NOM 9.3: Post neonatal mortality rate per 1,000 live births
					NOM 9.4: Preterm-related mortality rat per 100,000 live births

Smoking Prevention	Increase smoking screening and referrals of pregnant women to Mom's Quit Connection.	Reduce the percentage of women who smoke during pregnancy by 2% per year by 2025 (Baseline 2021 NJ PRAMS 2.2%).  Reduce the percentage of children who live in households where someone smoke by 2% by 2025 (Baseline 2018-2019 National Survey of Children's Health 8.7%).	NPM 14.1 Percent of women who smoke during pregnancy	ESM 14.1.1 – Number of pregnant women referred to Mom's Quit Connection	NOM 10: The percent of infants born with fetal alcohol exposure in the last 3 months of pregnancy  NOM 11: The rate of infants born with neonatal abstinence syndrome per 1,000 hospital births  NOM 23: Teen birth rate, ages 15 through 19, per 1,000 females  NOM 24: Percent of women who experience postpartum depressive symptoms following a recent live birth NOM 2 – Rate of severe maternal morbidity per 10,000 delivery hospitalizations  NOM 3 – Maternal mortality rate per 100,000 live births  NOM 4 – Percent of low-birth-weight deliveries (<2,500 grams)  NOM 5 – Percent of preterm births (<37 weeks)  NOM 6 – Percent of early term births (37, 38 weeks)  NOM 8 – Perinatal mortality rate per 1,000 live births plus fetal deaths  NOM 9.1 – Infant mortality rate per 1,000 live births
	T		T	I	NOM 9.3 – Post neonatal mortality
					rate per 1,000 live births  NOM 9.4 – Preterm-related mortality rate per 100,000 live births  NOM 9.5 – Sudden Unexpected Infant Death (SUID) rate per 100,000 live births  NOM 19 – Percent of children, ages 0 through 17, in excellent or very good health
Perinatal/Infant Health Reducing Black	Increase infant safe sleep	Increase	NPM 5: A) Percent	ESM 5.1: Percentage	NOM 9.1: Infant mortality rate per
Maternal and Infant	practices as reported by the PRAMS	infant safe	of infants placed to	of women reporting in	1,000 live births
Mortality	survey (on the back, no co-sleeping,	sleep by 1	sleep on their backs	PRAMS that they	
	no soft bedding).	percentage	B) Percent of	practice Infant Safe	NOM 9.3: Post neonatal mortality
		point by 2025 (Baseline PRAMS 2021: 19.49%).	infants placed to sleep on a separate approved sleep surface C) Percent of infants placed to sleep without soft objects or loose bedding	Sleep Environment (no co-sleeping, on back, and no soft bedding).	rate per 1,000 live births  NOM 9.5: Sleep-related Sudden  Unexpected Infant Death (SUID) rate per 100,000 live births
	Continue and expand the reach of Healthy Women Healthy Families Initiative,	Decrease Black non- Hispanic	SPM # 1: The percentage of Black non- Hispanic preterm	ESM 5.2: Rate of Black, NH preterm birth in NJ per 1,000	

Black Infant Mortality programs,	preterm births	births in NJ.	live births	
evidence-based interventions to	by 1			
reduce Black infant mortality and other disparities. These	percentage point by 2025			
programs include Group	(Baseline Birth			

prenatal care, the Doula	Certificate			
program, Fatherhood	2021: 13.1			
initiatives, and Breastfeeding	per			
support, groups. They are	1,000			
available to all birthing	Live			
	Births).	0014 #7		
persons (BP) with an	DITUIS).	SPM #7: Decrease the rate	ESM 5.3: Rate of	
emphasis on Black, NH BP.		of Black infant	Black, NH infant	
	Decrease Black	mortality in NJ	mortality in NJ per	
	Infant Mortality	per 1,000 live	1,000 live births.	
	rate by 1	births.		
	percentage			
	point by 2025			
	(Baseline Death			
	Certificate data			
	2020: 9.1 per			
	1,000 Live			
	Births).			

Improving Nutrition & Physical Activity  Child Health	Increase births in Baby- Friendly hospitals by promoting certification of hospitals and sharing breastfeeding data (birth certificate data and mPINC).  The Doula Learning Collaborative (DLC) provides training, workforce development, supervision support, mentorship, technical assistance (TA), direct billing, and sustainability planning to community doulas and doula organizations throughout the State of NJ. Community doulas have the inherent local knowledge and understanding that enables them to provide equitable and culturally responsive care to pregnant people during pregnancy, birth, and postpartum, which can potentially lower rates of adverse birth outcomes and increase breastfeeding rates.	Increase births in Baby- Friendly hospitals by 2% by 2024 (Baseline current number in 2023 of Baby- Friendly hospitals: 13)  Increase the percentage of women trained to become community doulas enrolled as NJ Family Care (Medicaid) Providers by 5% in 2025	NPM 4: A) Percent of infants who are ever breastfed B) Percent of infants breastfed exclusively through 6 months	ESM 4.1: Percentage of Births in Baby- Friendly Hospitals  ESM 4.2: Trained to become community doulas enrolled as N.1 FamilyCate (Medicald) Providers	NOM 9.1: Infant mortality rate per 1,000 live births  NOM 9.3: Post neonatal mortality rate per 1,000 live births  NOM 9.5: Sleep-related Sudden Unexpected Infant Death (SUID) rate per 100,000 live births
Promoting Youth Development	Increase completed ASQ developmental screens online as part of ECCS Impact Program.	Increase developmental screening among children, ages 9 – 35 months, by 2 percentage points by 2025 (Baseline National Survey of Children's Health 2020-2021: 34.8%).	NPM 6: Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year.	ESM 6.1: Promote parent- completed early childhood developmental screening using an online ASQ screening tool.	NOM 13: Percent of children meeting the criteria developed for school readiness (DEVELOPMENTAL)  NOM 19: Percent of children, ages 0 through 17, in excellent or very good health
Adolescent Health Promoting Youth Development & Reducing Teen Pregnancy	Number of bullying/suicide prevention presentations delivered by or supported by NJDOH Title V Build youth's capacity for self-awareness, social awareness, self-management, relationships, and decision-making helps build the core skills that teens need to refrain from bullying others and bounce back when they are bullied.  Implement evidence-based Teen Pregnancy Prevention models in high-need areas with African American and Hispanic teens aged 15-19.	Increase the number of adolescents participating in a bullying awareness and prevention program.  Increase the percentage of students completing at least 75% of an evidence-based pregnancy	NPM 9: Percent of 9- 12th graders who reported being bullied on school property or electronically bullied.  SPM 6 — Increase the percentage of students completing the	ESM 9.1 – Percentage of high school students who are electronically bullied (counting being bullied through texting, Instagram, Facebook, or other social media).  ESM 9.2 – Percentage of high school students who are bullied on school property.  ESM 9.3: Number of students (male and female) who completed at	NOM 16.1; Adolescent Mortality Rate Ages 10-19 per 100,000 NOM 16.3: Adolescent Suicide Rate Ages 15-19 per 100,000

				TOP program,	least 75% of an evidence-based Teen Pregnancy Prevention Model (Teen Outreach Program, Reducing the Risk or Teen PEP)	
		Adopt evidence-based youth engagement strategies aimed at increasing the percentage of students completing at least 75% of an evidence-based teen pregnancy prevention program (TOP program, Love Notes, Reducing the Risk, and Teen PEP) in counties/municipalities that are high risk.	prevention program (TOP program, Love Notes, Reducing the Risk, and Teen PEP) per year, by 5% by 2024 (Baseline 2021 Birth Certificate data: births to teens 19 and under 2,287).	Reducing the Risk, and Teen PEP per year.		
ŀ	Children with Special	Health Care Needs				
	Improving Access to Quality Care for CYSHCN	Identify and monitor transition to adulthood needs for CYSHCN and their families served through the Case Management Units (CMUs).  Explore youth and their parents' needs to facilitate transition with insurance, education, employment, and housing, and link them to community-based partners.	Increase the percentage of CYSHCN ages 12-17 yages 12-17 yagrs served by Special Child Health Services Case Management Units (SCHS CMUS) with at least one transition to adulthood service by 3 percentage points by 2025 (Baseline New Jersey Special Child Health Services, Family Care Center Services 2021: 45 0%)	NPM 12: Percent of adolescents with and without special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care.	ESM 12.1: Percent of CYSHCN ages 12-17 years served by SCHS CMUs with at least one transition to adulthood service	NOM 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

Improving Access to Quality Care for CYSHCN	Provide comprehensive care with physicians and allied health professionals, by partnering with patients and their families.	Increase the percentage of children and children with special health care needs, aged 0 – 17	NPM 11: Percent of children with and without special health care needs, ages 0 through 17, who have a medical	ESM 11.1: Percent of CYSHCN ages 0-18 years served by SCHS CMUs with a primary care physician and/or Shared Plan of Care	NOM 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system
	Provide a baseline for programmatic needs to increase the percentage of CYSHCN with a primary care physician and identify the 'next steps' needed to establish medical homes for CYSHCN.	years old, who have a medical home by 4 percentage points by 2025 (Baseline The New Jersey Special Child Health Services, Family Care Center Services 2021: 40.1%)	home.	(Spoc).	NOM 18: Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling  NOM 19: Percent of children, ages 0 through 17, in excellent or very good health  NOM 25: Percent of children, ages 0 through 17, who were not able to obtain needed health care in the
Improving & Integrating Information Systems	Universal newborn hearing screening began largely due to evidence that clearly demonstrated improved language and developmental outcomes in Deaf/hard of hearing children that receive Early Intervention services as soon as possible and ideally before six months of age.	By the end of the funding period at least 70% of children that are identified as having a permanent hearing loss as a result of newborn hearing screening will be enrolled in Early Intervention services within two months of the diagnosis.	SPM 3: Percentage of newborns who are discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening and who have outpatient audiological follow- up documented.		last year
Improving Access to Quality Care for CYSHCN	Special Child Health Services Unit Coordinators are expected to assign new BDARS referrals to a case manager for initial outreach within fourteen (14) days of referral. Adopt methods that facilitate an increase in the percentage of BDARS referrals that are assigned to a case manager within 14 days.	Increase the percent of live children registered with the Birth Defects and Autism Reporting System (BDARS) who have been referred to NJ's SCHS CMUS who are receiving services by 0.5% by 2025 (Baseline The New Jersey Special Child Health			
		Services, Family Care Center Services 2021: 95.9%).			
Improving Access to Quality Care for CYSHCN	Improve BDARS to reduce the time from referral to autism diagnosis.	Decrease the age of autism diagnosis by 1/2 year by 2025 (Baseline NJ Autism Registry 2021: 4.8 years old).	SPM 5: Age of Autism Diagnosis		

Improving & Integrating Information Systems	Monitor and guide service delivery to assure that all children have access to preventive oral health services.  Provide preventive interventions such as age-appropriate oral health education.  Promote the application of dental sealants and the use of fluoride, increasing the capacity of state oral health programs to provide preventive services.	Increase the percentage of children, ages 1 – 17, who had a preventive dental visit in the past year by 2% by 2022.	NPM 13.2: Percent of children, ages 1 through 17, who had a preventive dental visit in the past year.	ESM 13.2.1: Percent of children enrolled in Medicaid or CHIP who receive preventive and any dental services (CMS- 416).	NOM 14: Percent of children, ages 1 through 17, who have decayed teeth or cavities in the past <u>year</u> NOM 19: Percent of children, ages 0 through 17, in excellent or very good health
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# Acronym List

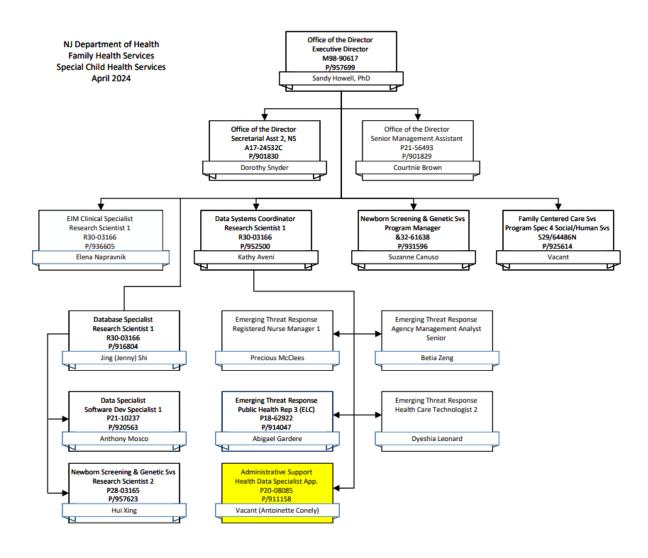
Full Name	Acronym				
General					
Black infant mortality	BIM				
Centers for Disease Control and Prevention's	CDC				
Community Health Worker	CHW				
Certified Nurse Assistants	CNAs				
Department of Children and Families	DCF				
Division of Developmental Disabilities	DDD				
Department of Human Services	DHS				
Department of Education	DOE				
Division of Vocational Rehabilitation	DVRS				
Evidence-Based Informed Strategy Measures	ESMs				
Family Health Services	FHS				
Federally Qualified Health Centers	FQHCs				
Health Resources Service Administration	HRSA				
Healthy Women, Healthy Families	HWHF				
Maternal and Child Health	МСН				
Maternal Child Health Bureau	МСНВ				
Maternal and Child Health Block Grant	MCHBG				
non- Hispanic	NH				
New Jersey	NJ				
National Outcome Measures	NOM				
National Performance Measures	NPMs				
Request for Application	RFA				
Request For Proposals	RFP				
State Priority Needs	SPNs				
Title V Program	TVP				

Title V staff	TVS					
Women Infants and Children	WIC					
Women's Health						
Colette Lamothe-Galette Community Health Worker Institute	CLG-CHWI					
Maternal Health Innovation	MHI					
Connecting NJ	CNJ					
Doula Learning Collaborative	DLC					
Maternal Child Health Services	MCHS					
Maternal, Infant, and Early Childhood Home Visiting	MIECHV					
Maternal Mortality Review Committee	MMRC					
Postpartum Depression and Mood Disorders	PPD-MD					
New Jersey Pregnancy Risk Assessment Monitoring System	PRAMS					
Reproductive and Perinatal Health Workforce	RPHW					
Perinatal Infant Health						
Fetal Infant Mortality Review	FIMR					
Substance use disorder	SUD					
Child Health						
Basic Screening Survey	BSS					
Early Childhood Comprehensive System	ECCS					
Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder	FAS/FASD					
National Survey of Children's Health	NSCH					
Adolescent Health						
Adolescents and young adults	AYA					
Child and Adolescent Health Program	САНР					
Teen Prevention Education Program	PEP					
Personal Responsibility Education Program	PREP					
Sexual Risk Avoidance Education	SRAE					
Teen Outreach Program	TOP					
Youth Risk Behavioral Surveillance	YRBS					
Children with Special Health Ca	re Needs					
American Academy of Pediatrics	AAP					
Autism Spectrum Disorders	ASD					
American Sign Language	ASL					
Birth Defects and Autism Registry	BDAR					
Birth Defects and Autism Reporting System	BDARS					
Critical Congenital Heart Defects	ССНД					
congenital Cytomegalovirus	cCMV					
Child Evaluation Centers	CECs					
Case Management Referral System	CMRS					

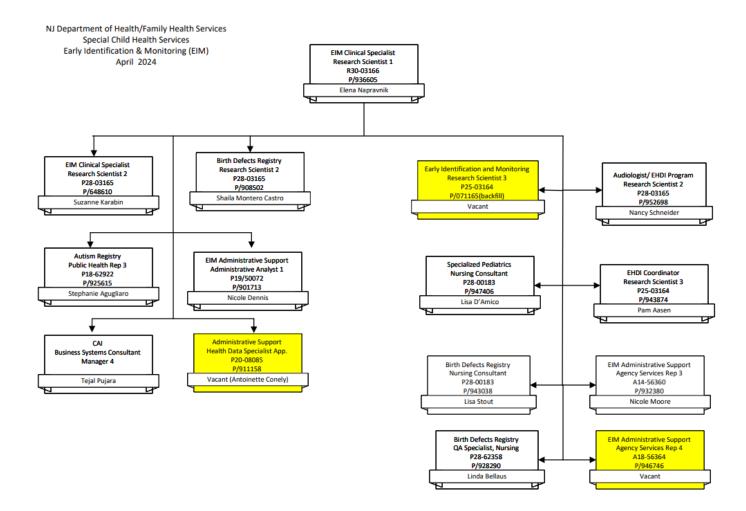
Case Management Units	CMUs
Statewide Community of Care Consortium	COCC
Children and Youth with Special Health Care Needs	CYSHCN
Data Systems and Emerging Threat Response	DSET
Early Hearing Detection and Intervention	EHDI
Early Identification and Monitoring	EIM
Early Intervention Services	EIS
Expanded Laboratory Capacity	ELC
Family Centered Care Services	FCCS
Individual Service Plan	ISP
Newborn Biochemical Screening	NBS
New Jersey Early Intervention Services	NJEIS
New Jersey Immunization Information System	NJIIS
NJ Stakeholders	NJSH
Newborn Screening Follow-up and Genetic Services	NSGS
Pediatric Tertiary Care	PTC
Special Child Health Services	SCHS
Special Child Health Services Case Management	SCHSCM
Shared Plan of Care	SPoC
Specialized Pediatric Services Program	SPSP

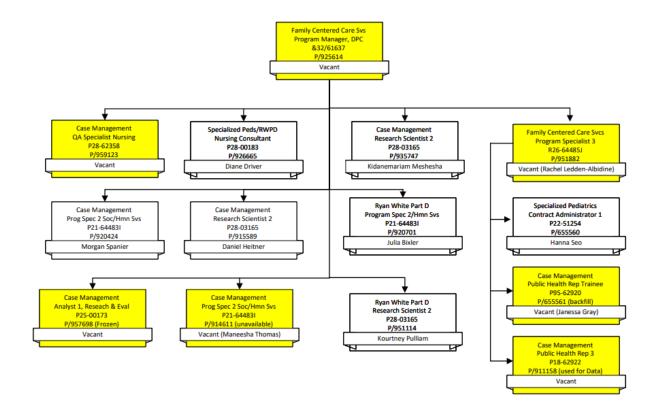
## **Organizational Charts**

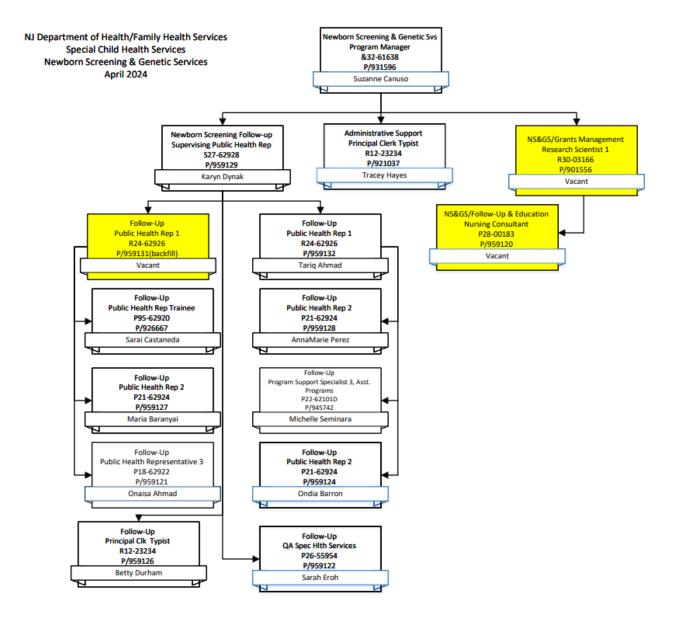
# **Special Child Health Services**



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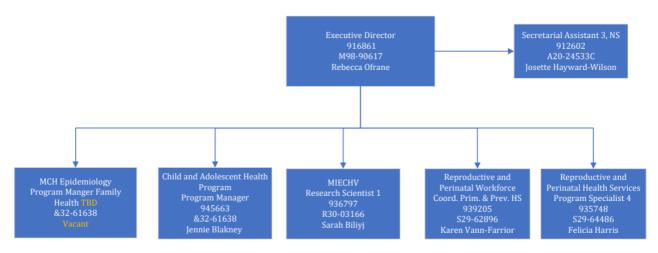




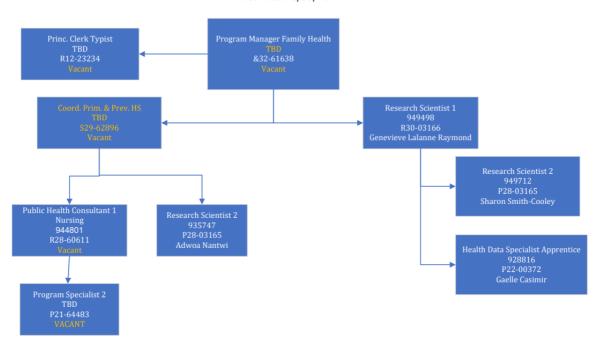


# Maternal & Child Health (MCH) Services

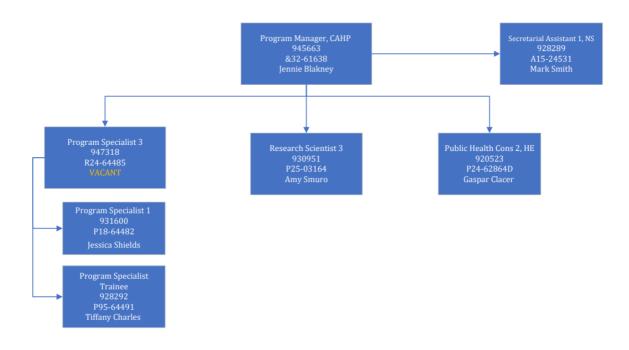
#### NJ Dept. of Health Family Health Services: Maternal & Child Health Services Office of the Director Last Edited: 3/30/2024



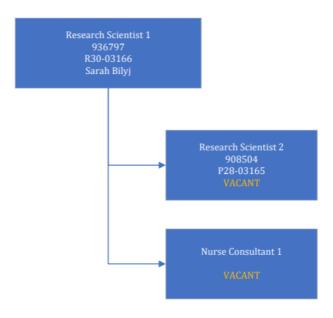
#### NJ Dept. of Health Maternal and Child Health Services: MCH Epidemiology Last Edited: 3/30/2024



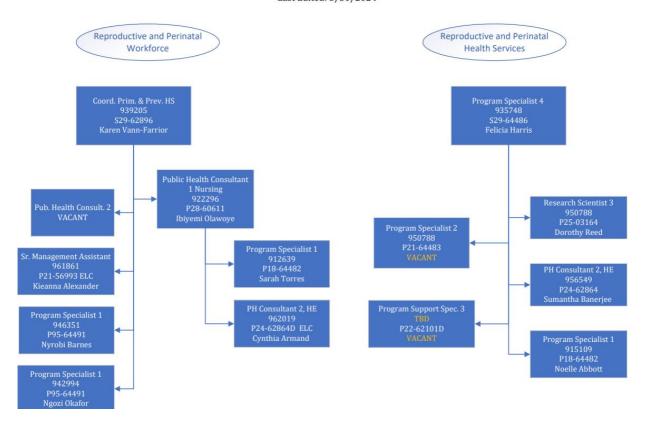
#### NJ Dept. of Health Maternal & Child Health Services: Child & Adolescent Health Program Last Edited: 3/30/2024



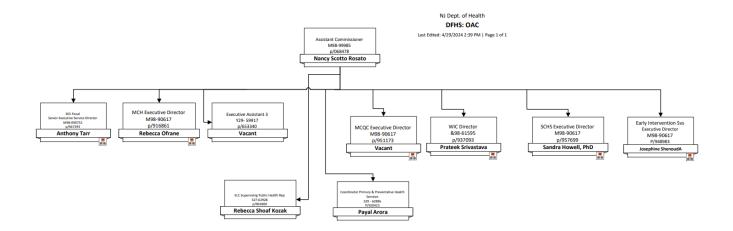
NJ Dept. of Health
Maternal & Child Health Services: Maternal Infant and Early Childhood Home Visiting
MIECHV
Last Edited: 3/30/2024



#### NJ Dept. of Health Maternal & Child Health Services: Reproductive & Perinatal Health Services & Workforce Last Edited: 3/30/2024



# Family Health Services Overview Org. Chart



# VI. Title V MCH – Title XIX Medicaid Inter-Agency Agreement (IAA): 2023 Letter; updated 2024 letter currently updating for submission July 2024

\*NOTE: This Interagency Agreement is being updated with new information and new signatures. It will be submitted with the FFY26 application once it is reviewed and approved by both DoH and DHS.

Interagency Letter of Agreement Between the State of New Jersey Department of Health and
Department of Human Services,
Division of Medical Assistance and Health Services

This letter of agreement between the State of New Jersey Department of Health (DOH) and Department of Human Services (DHS), Division of Medical Assistance and Health Services (DMAHS) is intended to promote the coordination of DOH's Maternal and Child Health Services Title V Block Grant with the Title XIX Medicaid Medical Assistance Program (Medical Assistance Program) in New Jersey.

Title V programs have great expertise in providing an infrastructure and access to services related to maternal and child health that Medicaid in turn can build upon. Title V programs have knowledge in developing model programs and materials that can be used by the Medical Assistance Program. Title V personnel are also skilled in providing outreach services to Medicaid beneficiaries thus enabling access on behalf of the Medical Assistance Program.

The purpose of this letter of agreement is to describe the respective roles and responsibilities of each agency in their coordination work to avoid duplication of services and effort.

The Maternal and Child Health (MCH) Services Block Grant and the Medical Assistance Program, authorized by Title V and Title XIX of the Social Security Act (SSA), serve complimentary purposes and goals. Coordination and partnerships between the two programs greatly enhance their respective abilities, increase their effectiveness, and guard against duplication of effort. Such coordination is the result of a long series of legislative decisions that mandate the two programs to work together. Interagency Agreements (IAAs), required by both Title V and Title XIX legislation, can serve as a key factor in ensuring coordination and mutual support between the two agencies (or divisions within an agency) that administer the two programs.

DOH, Division of Family Health Services (FHS), is responsible for administering a program of maternal and child health services (administered under the Maternal and Child Health Block Grant under Title V of the Social Security Act), pursuant to N.J.S.A. 26:1A·37.

DHS, DMAHS, is responsible for administering the Medical Assistance Program, pursuant to N.J.S.A 30:40-5; and As the State-designated Agency to administer the Maternal and Child Health Services Title V Block Grant program, the DOH acknowledges its responsibility to coordinate with DMAHS in administration of Title V programs.

As the State-designated Agency to administer the Medical Assistance Program in New Jersey, DMAHS acknowledges its responsibility to coordinate with DOH in administration of the Medical Assistance program.

This letter of agreement represents the continued commitment of each agency to coordinate with the other agency to avoid duplication of services and effort.

Therefore, to carry out their assigned duties to further the public good, the parties agree to the following:

#### Responsibilities of Both DOH and DMAHS shall:

- 1. Coordinate policies and procedures that impact health care services or the delivery of health care services to maternal and child health populations, including children with special health needs.
- 2. Share information regarding case management services, as permitted by applicable laws and separate data sharing agreements, and coordinate case management services, when appropriate, with all interested parties including Medicaid Managed Care Organization case managers.
- 3. Notify each other of any changes in criteria or standards relating to the provision of services pursuant to the Maternal Child Health Title V Block Grant or Medical Assistance Program for pregnant women, mothers and children prior to such changes.
- 4. Notify each other of any known changes in federal or State statutes, regulations, or policies that would impact programs that are administered under the Maternal and Child Health Title V Block Grant or Medical Assistance.
- 5. Identify how the DOH and DMAHS can work together to identify individuals within the maternal and child health population, including children with special health care needs, in need of medical and remedial services.
- 6. Share appropriate and relevant aggregate data affecting health status or delivery of health care services to the maternal and child health population, including children with special health care needs.
- 7. Meet at least annually to review any proposed revisions regarding case management services.
- 8. Agree that the use or disclosure of any individually identifiable health information concerning either program's participants shall be limited to purposes directly connected with the administration of each agency's programs or provision of supports and services and prevent any unauthorized use or disclosure of protected health information in accordance with applicable federal, State, and local laws. Any exchange of confidential information between the Departments will be documented and authorized through a memorandum of agreement for data sharing.
- 9. Establish appropriate administrative, technical and physical safeguards to protect the confidentiality of the information resulting from the administration of Maternal and Child Health Programs and Medical Assistance.

#### **Responsibilities of DOH:**

1. <u>Special Child Health and Early Intervention Services (SCHEIS)</u> DOH shall:

- i. Provide support and collaborate with OHS on education, training, and program development relating to diagnosis and reporting requirements for birth defects including critical congenital heart defects, hearing loss, and autism.
- ii. Meet at least annual with DMAHS to improve access to services for children with reportable birth defects, hearing loss and autism.
- iii. Ensure that the Special Child Health Services case management network is available for the provision of case management services for children with special health care needs from birth to twenty-one (21) years of age.
- iv. Establish quality measurements for appropriate outcomes.
- v. Act as the primary contact for the vendor responsible for the Medicaid fund recovery.
- vi. Ensure that early intervention services agencies comply with New Jersey Early Intervention Services (NJEIS) criteria.
- vii. Provide assistance and input to DMAHS for the development of Medicaid manuals and regulations relating to the Early Intervention Medicaid Initiative (EIMI).
- viii. Develop procedures for the monitoring of EIMI.
- ix. Assure that State matching funds are available through NJEIS.
- x. Report to DMAHS, the costs of DOH's administrative activities that are reasonable and necessary to support the requirements of EIMI.
  - 2. Child Health:

#### DOH shall:

- i. Provide support and collaborate with DMAHS on education, training, and program development relating to lead poisoning prevention.
- ii. Promote and facilitate enrollment of children into Medicaid and/or NJ FamilyCare.
  - 3. Childhood Lead Poisoning Prevention Surveillance System (CLPPSS):

#### DOH shall:

- i. Ensure quality monitoring of lead information, inspections and abatements.
- ii. Meet at least annually with DMAHS to improve lead screening efforts and case manage children with elevated blood lead levels.

#### **Responsibilities of DMAHS:**

1. Special Child Health and Early Intervention Services (SCHEIS)

#### DMAHS shall:

- i. Meet at least annually with DOH to ensure timely and accurate program operation.
- ii. Provide DOH with individual Medicaid participant claims data when the Medicaid participant requests DMAHS to provide their claim data to the DOH, and provide aggregate data to DOH, as needed, regarding children with birth defects, hearing loss and autism.
- iii. Provide NJEIS with updates and changes to Medicaid regulations.
- iv. Provide technical assistance, as needed, regarding requirements and specification for claims submission, processing and data reporting for Early Intervention Medicaid Initiative (EIMI).
- v. Submit claims to the federal government to draw down federal Medicaid funding for services provided under EIMI.
- vi. Assist DOH in maximizing federal reimbursement for the costs of allowable administrative activities.

#### 2. Child Health:

## DMAHS shall:

- i. Provide support to and collaborate with DOH on education, training, and program development relating to lead poisoning prevention.
- ii. Use the DMAHS website and DMAHS staff presentations at interdepartmental meetings to get information out about NJ FamilyCare, lead screening, and issues relating to children with special health care needs.

## 3. Childhood Lead Poisoning Prevention Surveillance System (CCLPPSS):

## **DMAHS** shall:

i. Coordinate with DOH to improve lead screening efforts and case management of children with elevated blood lead levels.

This letter agreement shall become effective upon signing. This agreement may be reviewed and considered for expansion, modification, or amendment at any time upon agreement of both parties. Data sharing needs set forth in this agreement will be detailed and governed by separate data sharing

DOH Signature

agreements.

Lisa A. Asare, MPH Assistant Commissioner, FHS, DOH

> Jennifer Jacobs Director, DHMAS, DHS