

Governor's Council on the Prevention of Developmental Disabilities



Annual Report for Fiscal Year 2020



State of New Jersey
Phil Murphy, Governor
Tahesha L. Way, Lt. Governor

NEW JERSEY HUMAN SERVICES



**Division of
Developmental
Disabilities**

Department of Human Services
Division of Developmental Disabilities
Sarah Adelman, Commissioner

GOVERNOR'S COUNCIL ON THE PREVENTION OF DEVELOPMENTAL DISABILITIES

ANNUAL REPORT FOR FISCAL YEAR 2020

The Governor's Council on the Prevention of Developmental Disabilities (Council) and the Office for the Prevention of Developmental Disabilities (OPDD) were created by Public Law 1987, Chapter 5, and amended by Public Law 2000, Chapter 82. OPDD is based in the Department of Human Services' Division of Developmental Disabilities (DDD) and works with the Council and its Task Forces to pursue a common charge - the prevention of intellectual/developmental disabilities (IDDs) in the State of New Jersey. The Council serves as an advisory body to the OPDD and makes recommendations to the Commissioner of the Department of Human Services (DHS) regarding policies and programs to reduce or to prevent the incidence of intellectual/developmental disabilities in New Jersey.

The Council is comprised of 25 public members, who are appointed by the Governor. Members serve a three-year term. Additionally, the Council includes New Jersey State Commissioners, or their designees, of the Departments of Human Services, Community Affairs, Education, Health, and Environmental Protection, and the Secretary of State, serving as ex officio members.

The Council reports annually to the Governor and the Legislature concerning the status of prevention programs in the state. Without compensation, public members of the Council, in partnership with the members of the Fetal Alcohol Spectrum Disorder and other Perinatal Addictions Task Force and Interagency Task Force on the Prevention of Lead Poisoning, imbue this work with a high level of intensity and dedication.

Fiscal Year 2020 Activities

Despite the challenges of the COVID-19 pandemic, the Council adjusted to virtual meetings and correspondence to maintain focus on its advisory mission to the OPDD and DHS. Throughout the fiscal year the Council and OPDD reviewed intellectual/developmental disability prevention programs through field visits, project meetings, and presentations to the Council by State and other institutions working in the field of prevention (see Appendix A). In FY 2020, the Council focused on the following activities:

1. Current Issues in the Prevention of Developmental Disabilities

The issues and concerns that can impact the proper development of a child are varied. The Council takes time, at every meeting, to review child development topics that become apparent in the work conducted by its members. The identification and possible actions to be taken regarding matters that can affect

the development of children is of paramount concern to the Council. Several guest speakers presented information on matters affecting issues of health and support for pregnant women and child development, including:

- Early diagnosis and treatment of Autism/Autism Spectrum Disorders (ASD) and other intellectual/developmental disabilities.
- Importance of dietary folate for women of childbearing age.
- Promotion of messaging regarding Maternal Health among college students.
- Lead in drinking water.
- Community engagement strategies regarding lead and FASD awareness.
- Lead screening in the State of NJ.
- Early Intervention in the State of NJ and its role with children with elevated blood lead levels.
- Department of Health, Pregnancy Risk Assessment Monitoring System (PRAMS)
- Reducing child poverty and poverty's impact on child development.
- As required by the New Jersey State Ethics Commission, Council members underwent Special State Officer Ethics Training.

2. New Jersey Task Force on Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions

Fetal Alcohol Spectrum Disorder (FASD), a developmental disability resulting from fetal alcohol exposure during pregnancy, is 100% preventable. The mission of the New Jersey Task Force on Fetal Alcohol Spectrum Disorders and other Perinatal Addictions (FASDTF) is to; provide education regarding the causal relationship between the exposure to alcohol and other substances during pregnancy and the incidence of Fetal Alcohol Spectrum Disorders (FASD); and promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

The FASDTF met in July and December 2019 as well as during January 2020. Conference calls occurred in October and November 2019 as well as during January and June 2020.

The members of the FASDTF work on the front lines of FASD prevention. They engage with community organizations and policy professionals regarding news, research, best practices and programs, locally and nationally, regarding FASD. The FASDTF focused on increasing awareness in New Jersey about FASD and perinatal addictions among the public and healthcare professionals.

During FY 2020, the following issues and initiatives were determined to be priority work items by the FASDTF:

- FASD Awareness Day/Month started on September 9, 2019. The FASDTF worked with its partners to create awareness of FASD and maternal health in general. Some of these activities have targeted schools and university settings in order to focus on young people.
- The importance of FASD education as a required competency for certification, licensure and continuing education for social workers. There is misinformation and stigma about alcohol use during pregnancy. Education is critical in order for social workers to become equipped to identify, refer and assist with appropriate treatment for this underserved population.
- Discussion of New Jersey Pregnancy Risk Assessment Monitoring System (NJ PRAMS) which is a joint project of the New Jersey Department of Health and the Centers for Disease Control and Prevention.
- The [FASDNJ.org](https://www.fasdnj.org) website was an area of focus for the FASDTF in FY 2020. Establishing a strong online presence is important to the dissemination of needed information for a safe and healthy pregnancy. New Jersey's FASD website assists individuals and families regarding the prevention of FASD by providing links to respected maternal child health resources as well as useful information pertaining to the navigation of New Jersey's FASD service systems.
- In FY2019, the FASDTF helped create a comprehensive guidebook intended to assist anyone in need of FASD related services to find their way through New Jersey's state system of programs and services. The FASD guidebook appears on the FASDNJ website. The FASDTF continued, in FY 2020, to promote this document around the state in order to assist individual citizens and agencies in understanding the New Jersey systems that provide assistance to people with an FASD and other intellectual/developmental disabilities.

3. Interagency Task Force on the Prevention of Lead Poisoning

Lead remains a significant preventable environmental health threat to New Jersey's children. Our state's rich industrial history and the high number of homes built before 1978 contribute to this ongoing issue, which is critical for preventing intellectual and developmental disabilities. Although lead was banned for residential use in 1978, it continues to impact families' lives. Aging water infrastructure and the dangers of lead paint drive the efforts of the Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) to minimize lead's harmful presence in New Jersey.

The immediate impact of lead can be profound and may have multigenerational effects. New Jersey is the most densely populated state. In our state, residents are at higher risk for elevated blood lead levels because of substantial amounts of lead contamination.

The mission of the Lead Task Force is to:

- Reduce childhood lead poisoning;
- Promote lead-safe and healthy housing;
- Support education and blood lead screening; and
- Support interagency collaboration.

Lead Task Force members include representatives from state agencies charged with addressing the health and environmental problems caused by exposure to lead, including the Departments of Community Affairs, Environmental Protection, and Health. The U.S. Environmental Protection Agency, Rutgers University, and many local public health, housing, and social service agencies also participate on the Lead Task Force.

The following issues and items received attention from the Lead Task Force during FY 2020:

- Lead Task Force members continued their small group work focusing on the screening of children; reporting of data and enrollment of children with elevated blood lead levels in Early Intervention.
- The Screening of Children small group discussions included the following:
 - How diverse, strong partnerships were identified as a key to screening success.
 - How to identify high-risk and uninsured individuals at locations such as Special Supplemental Nutrition Program for Women, Infants and Children (WIC) offices and Family Success Centers.
 - How to utilize the existing trust among existing home-based partnerships like Nurse Family Partnership / Healthy Start.
 - Utilizing faith-based groups to help connect with important parties.
- The Data Reporting small group discussions included the following:
 - New lead data systems.
 - What should a public data system look like?
 - Smaller levels of geography including more towns (not just big municipalities).
 - Utilization of LeadTrax.
 - Data accessibility including how different parties need to be able to see necessary child data.
 - Data quality including up-to-date and accurate data and the cleaning up of old data.
- The Early Intervention small group discussions included the following:
 - Organize training of Early Interventionists in how to best work with families/children with elevated blood lead levels (EBLs).
 - Systematically train school nurses in lead poisoning prevention, symptoms, and interventions.

- Instruct special education staff in lead poisoning prevention, symptoms, and interventions.
 - Work with teacher training programs to update curriculum to include issues related to lead poisoning.
 - Offer a panel on lead at the NJEA annual conference.
 - Advise Childhood Lead Poisoning Prevention Program (CLPPP) to restart trainings of school district staff: Head Start, school nurses, and more.
- The Lead Task Force heard from a number of speakers on subjects intended to assist them with their work. Speakers included:
 - Dr. Puthenmadam Radhakrishnan & Harriet Lazarus from the NJ Chapter of the American Academy of Pediatrics (AAP) regarding the AAP's lead poisoning prevention work in NJ.
 - Dr. Susan Evans from the NJ Department of Health regarding the state's Early Intervention system.
 - Alexis Ziegler from the NJ Department of Education regarding the transition from Early Intervention to preschool special education programs and the process for children to be identified as a preschooler with a disability.
- National Childhood Lead Poisoning Prevention Week was observed from October 20-26, 2019. Lead Task Force members participated in activities throughout the state of NJ. Some of these activities included:
 - Lead screenings and health fairs;
 - CLPPP education for children;
 - Lead education events;
 - Distribution of home kits, including items such as sponges, baking soda, vinegar, lead surface test kits, water test kits, etc; and
 - Lead screenings at schools in partnership with school nurses.

Office for the Prevention of Developmental Disabilities FY2020 Grant Funding

The OPDD funds agency projects that help prevent intellectual/developmental disabilities. FY 2020 started a new three-year funding cycle. Projects funded during fiscal years 2020 – 2022 are as follows:

SPAN Parent Advocacy Network - \$184,975 per year

The *Empowering Women in Community Leadership for Healthier Families* project is intended to prepare women of childbearing age as Peer Leader Liaisons (PLLs) to enhance existing state and community-based efforts to reduce the risk of preventable Intellectual/Developmental Disabilities (IDDs), specifically fetal alcohol syndrome (FAS), fetal alcohol syndrome disorders (FASD) and those caused by lead poisoning. SPAN will provide leadership training and education,

to support and facilitate community engagement, for women of childbearing age for whom their children are at risk of elevated blood lead levels and/or at risk of being born with FAS/FASD. By the end of the third year, the project is expected to reach communities in nearly every county and develop the peer leadership skills of 315 to 420 diverse women. These women will participate in and have a voice in local and statewide decision-making and advocacy forums concerning FAS/FASD and lead poisoning prevention.

The goal of this project focuses on developing community engagement in prevention of Intellectual Disabilities resulting from FASD and Lead poisoning for women of childbearing age using a Collective Impact Model. The project intends to increase knowledge and skills for women in high-risk communities by building parent leaders who can provide peer-to-peer support. Focus groups, support groups and trainings have trained more than 300 women in communities from throughout NJ. Some of the trainings, including the Women's Summit, were performed virtually as a result of COVID-19 restrictions, which were executed in response to the pandemic.

Prior to March 2020, the agency reports having been on track to meet its first year goals. Due to COVID-19 a directive was issued, by agency leadership, to stop all in person meetings, peer group activities and trainings until further notice. Virtual leadership trainings replaced in-person trainings. A Parent to Parent program allowed participants to engage in parent support group virtual activities. Leadership training, originally scheduled to be completed in the 3rd quarter; was delayed and conducted virtually during the 4th quarter. Some additional activities needed to be postponed to the first quarter of FY 2021. Based upon agency reporting, nearly all 1st year activities occurred.

Partnership for Maternal & Child Health of Northern NJ (PMCHNNJ) - \$185,000 per year.

In order to accomplish its objectives, the project planned to implement the National Organization on Fetal Alcohol Syndrome (NOFAS) K-12 Education and Prevention Curriculum in schools, after school programs, CBOs, and school districts serving target municipalities. During the first year of the proposed project, PMCHNNJ intended to reach schools where current Partnership programs exist, and will reach other schools and municipalities with a 15% increase in school recruitment goal for each year of the program. The K-12 curriculum addresses many important topics for school-aged students, such as: FASD, the consequences of prenatal alcohol consumption on human development, overall effects of alcohol on human development, addictions, and acceptance of all people regardless of individual capabilities or disabilities. The curriculum provides FASD educational materials and lesson plans that can be implemented in classroom settings with age-appropriate information and activities, teacher background information about FASD, and a sample family letter explaining the planned unit of study.

As with the other projects funded by the OPDD in FY 2020, PMCHNNJ was forced to modify its program due to the COVID-19 pandemic. The agency connected with the OPDD and modified their deliverables by adding virtual presentations in order to replace face-to-face education and marketing efforts. Project evaluation tools as well as parental consent forms were made available online. As a result of these changes, the agency noted decreased data availability for evaluation of the presentations. Additional prevention education projects were added to the program (Kits for Kids and three professional films). This project has reached a large number of school districts and developed internet-based education programs to address a broad area of topics relevant to various aged student groups.

Agency reports provide outcome assessment data, which demonstrate the educational effectiveness of their programming. The program has reached a large group of students and provides pre and post-test assessment of student's knowledge.

Rutgers School of Public Health - \$185,000 per year

The focus of this project are young children, attending a large pediatric practice, whose parents report an early delay in social communication development, that is, children who are at greater risk of Autism Spectrum Disorder (ASD). Children's social communication development will be evaluated through use of a simple, standardized, validated questionnaire – the Psychological Development Questionnaire for Toddlers (PDQ-1) to be completed by parents with children receiving pediatric care from the Rutgers—New Jersey Medical School (NJMS) Pediatric Continuity Care Clinic (PCCC). The PCCC is a medical anchor of Central Ward Newark. The PCCC serves as the community's first line of expertise with regard to detection of learning and developmental problems and in assisting families with special needs children. The population to be served by this project will be approximately 6,000 to 7,000 Newark-residing children between the ages of 18 and 24 months and their parents, served by the PCCC, in 2020 and 2021. Most of the screened children will be in the highest risk group for late evaluation, late diagnosis and late receipt of interventions. This project is intended to have a high impact on this population of children with ASD, who, on receiving timely autism screening, will go on to be served by their Early Intervention Program (EIP).

The project started enrolling subjects in January 2020 following research preparation activities. To date, the agency reports that more than 50 families have been enrolled and 7 children between the ages of 18 and 30-month have tested positive for ASD using the PDQ-1 or MCHAT. However, due to COVID-19 restriction, the project operations were suspended between March 16th and June 30th. Activities resumed during the July/August period. As a result, the agency reports having lower rates of enrollment in the first year of the project. The project leader notes that the project will adopt additional strategies to continue their work. Included will be the use of tele-medicine media for recruitment and continued (virtual) autism screening. Additionally, the PDQ-1 screener will be inserted as a

standard component of the pediatric 18 and 24-month examination and the consent form will be modified to allow study enrollment by verbal consent. The agency reports the following additional benchmarks:

- The enrollment of 57 families screened for ASD using PDQ-1 and MCHAT.
- Seven children screened positive for ASD (considered at risk).
- Mom2Mom peer counselors have contacted all guardians of children who screened positive to assist in receiving EIP services and be referred to a developmental specialist for further evaluation for autism and/or intellectual/developmental disability.
- Project staff is continuously in contact with families of children who screened positive.
- The investigators have entered data for all screened children in the study database (REDCap).
- The investigators have secured IRB approval to implement ASD screening using the PDQ-1 at Essex county Early Intervention Program.

Appendix A

Presentations to the Governor's Council on the Prevention of Developmental Disabilities

9/11/2019

- Spina Bifida Research Network Healthy Now Healthy Later Project Review
Dr. Roberta Kestenbaum, Spina Bifida Resource Network

1/29/2019

- Lead in Drinking Water Review
Patricia Ingelido & Kat Burkhard, NJ DEP

6/24/2020

- Empower Women Project
Nicole Pratt, Parent Advocacy Network (SPAN)

Appendix B

Governor's Council on the Prevention of Developmental Disabilities FY 2020 Membership

State of New Jersey Government Representatives

Adam Bucon, LSW	Department of Human Services
Mary M. Knapp, MSN, RN	Department of Health
Kenneth Richards	Department of Education
Jennifer Underwood	Department of Community Affairs
Gloria Post, Ph.D., DABT	Department of Environmental Protection
Rowena Madden	Department of State

Public Members

1. Dorothy Angelini, MSN
2. Jeananne Arnone, RN, BS
3. Caroline Coffield, Ph.D.
4. Mary DeJoseph, DO
5. Forest Elliot, M.A., LDTC
6. Fran Gallagher
7. Carol Ann Hogan, M.S. Ed.
8. William Holloway, Ph.D.
9. Martin Johnson
10. George Lambert, MD
11. Lynne Levin, OTR/L
12. Barbara May, RN, MPH
13. Michael McCormack, Ph.D., FACMG
14. Judith Morales, MSW, LCSW
15. Munir Nazir, MD
16. Beatriz Osterheld
17. Daniel Ranieri
18. Marlene Schwebel, JD, APN
19. Alyce M. Thomas, RD
20. Yvonne Wesley, RN, Ph.D.
21. Thomas Westover, MD
22. Jean Wiegner, CSNA
23. Leon Zimmerman
24. Ilise Zimmerman, MS

Staff

Jonathan Sabin, LSW
Director, Office for the Prevention of Developmental Disabilities