

# Governor's Council on the Prevention of Developmental Disabilities



## Report for Fiscal Year 2021



**State of New Jersey**

Phil Murphy, Governor    Sheila Oliver, Lt. Governor



**Department of Human Services**

Sarah Adelman, Acting Commissioner

**Division of Developmental Disabilities**

## **Governor's Council on the Prevention of Developmental Disabilities**

### **Report for Fiscal Year 2021**

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. 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 2021 Activities**

The challenges associated with COVID-19 carried over from last year and impacted the work of the Council during Fiscal Year (FY) 2021. The body met but, did so via the utilization of online meeting platforms. The Council and OPDD continued to work with the agencies, tasked with OPDD funded projects, to make needed modifications to their activities. The Council took pride in its ability to remain flexible and work with its partners and maintain its advisory mission to the OPDD and DHS. The Council and OPDD reviewed intellectual/developmental disability prevention programs throughout NJ. Efforts included online reviews, project meetings, and presentations to the Council by State and other institutions working in the field of prevention (see Appendix A). In FY 2021, 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. The following topics were reviewed:

- Intersection of developmental disability prevention data and Medicaid.

- FASD awareness among school aged children.
- Early diagnosis and treatment of Autism Spectrum Disorders (ASD) and other intellectual/developmental disabilities.
- Healthy food and the importance of dietary folate.
- Maternal and infant health outcomes during COVID-19.
- Lead in drinking water.
- Physician–patient racial concordance and disparities in birthing mortality for newborns.
- 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).
- NJ Cannabis Regulatory Enforcement Assistance, and Marketplace Modernization Act.
- Cannabis use and pregnancy.
- 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 (FASD Task Force)**

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.

FASDTF members met via online platforms in July, August, November and December 2020 as well as during January, February and May 2021.

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

- FASD Awareness Day/Month started on September 9, 2020. The FASDTF worked with its partners to create awareness of FASD and maternal health in general. Some of these activities targeted schools and university settings.

- FASD Guidebook promotion included mailing copies to select Child Evaluation Center (CEC) staff and monitoring how the copies are being utilized or not being utilized.
- Website Promotion activities continued including planning around updates and regular content reviews.
- The impact of COVID-19 on FASD prevention was reviewed. Task Force members discussed the reported increase in alcohol use during the pandemic and the increased accessibility of alcohol via curbside pickup and home delivery. People are now drinking more at home and children are watching parent's behavior with alcohol. Members also conferred about the advantages and disadvantages of FASD prevention professionals working from home. Task Force members reported being able to attend more meetings to promote FASD prevention but missed connection of meeting parents, colleagues and students in person.
- The NJ CREAMMA (NJ Cannabis Regulatory Enforcement Assistance, and Marketplace Modernization Act) was reviewed.

### **3. Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force)**

Lead is one of the leading preventable environmental health threats to New Jersey's children. Our state's extensive industrial heritage and high proportion of pre-1978 housing continue to keep it as an important intellectual/developmental disability prevention issue. Despite its ban for residential use in 1978, lead continues to affect the lives of families. Our country's aging water delivery infrastructure in addition to the hazards of lead paint, motivate the members of the Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) to reduce lead's dangerous foot print in NJ.

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. Members included are from the Departments of Human Services, 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.

In FY 21, the Lead Task Force met in December 2020 and during February and May 2021. The task force reviewed current lead issues impacting the State of New Jersey during each meeting. The following issues and items received attention from the Lead Task Force during FY 21:

- The Lead Task Force received updates from the Northern, Central and Southern Lead Coalitions in order to learn about new and ongoing lead poisoning prevention initiatives around the state of NJ.
- The Lead Task Force received regular updates pertaining to lead initiatives at the Department of Health and Department of Community Affairs.
- 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:
  - Since the pandemic, lead poisoning was getting worse:
    - Screening rates were down 40%.
    - 4% uptick in children with an EBLL.
    - Hospitalizations for Lead were up.
  - During the pandemic, many screening locations closed. The Screening workgroup considered alternative options such as mobile units, drive-up testing (and drive-up in buses), mouth saliva lead test (still in approval/regulatory process) possibly in conjunction with vaccine deployment and/or COVID testing, and mail/return from home.
  - Loaning Lead Care II analyzer to pediatrician's offices.
  - Initiate a School Screening pilot program: local Health Departments, schools, and community-based organizations can request Lead Care II analyzers, plan for, and execute a Screening and Education event at their local school.
  - Working on draft of flowchart and best practice guide to create and execute screening pilot at school or other community location.
  - Health insurance representatives have consistently brought up the lack of screening data available for their processes. The issue seems to be a significant hurdle to overall communications and, eventually, raising screening rates.
  - Screening Group's "plug & play" model that shows best practices for screening. Community groups can be successful with this model because they have the preexisting relationships.
- The Data Reporting small group discussions included the following:
  - Health insurance companies would like to get data about when children are screened at places other than their doctors.
  - Creation of a lead-safe housing registry to show where buildings had been remediated.
  - Utilization of LeadTrax.
  - Insurers interest in access to LeadTrax so they know what is happening with their members.
  - The need to think about all sources of lead-paint, water, soil.

- o Idea to revive the Safe Housing Registry effort, which would have listed properties that are safe from lead (e.g., no lead service line (LSL) or lead paint.) Years ago, Rutgers University created the beginnings of such a database, possibly in cooperation with DCA.
- o Comprehensive mapping of lead sources - this idea, which also has been considered in the past, would secure data on key lead-factors, such as elevated blood lead levels (EBLLs) and LSLs, and depict them on one map, preferably by census tract level. Though such a document would be an important step forward for guiding communications, disclosure, and remediation, access to data has been difficult to acquire.
  - DEP staff indicated that their Department's Environmental Public Health Tracking Program is actively developing a related set of maps for the lead issue using information on the age of housing, drinking water test results, and lead in soil (i.e., DEP database). The tool, when completed, would be available for public scrutiny. DEP does not have data on EBLLs, however, therefore a key question is whether a data agreement of some type could be struck with DOH.
- The Early Intervention small group discussions included the following:
  - o Systematically train school nurses in lead poisoning prevention, symptoms, interventions.
  - o Systematically train special education staff in lead poisoning prevention, symptoms, interventions. Child study teams, Principals and other education administrators.
  - o Advise CLPPS to restart trainings of school district staff: Head Start, school nurses, and more.
  - o Organize training of Early Interventionists in how to best work with families/children with EBLs.
  - o Extend invitations to school boards and district staff to attend Lead Task Force meetings.
  - o Work with teacher training programs to update curriculum to include issues related to lead poisoning.
  - o Review regulatory landscape of lead and special education; if a gap is identified, draft recommendations to better serve children with lead by IDEA Part B Ages 3-5, 5-21.
  - o Offer a panel on lead at NJEA annual conference.
  - o Extend invitations to school boards and district staff to attend Lead Task Force meetings.
- The Lead Task Force heard from speakers on subjects intended to assist them with their work. Speakers included:
  - o Matthew F. Csik (New Jersey American Water) – Lead & Water
  - o Janice Prontnicki, MD, NJ Child Evaluation Centers (CEC's) & Lead

- National Childhood Lead Poisoning Prevention Week was observed from October 25-31, 2020. Lead Task Force members participated in activities throughout the state of NJ. Some of these activities included:
  - Coalition hosted virtual events
    - Children’s Keep Me Lead Free Workshop via Zoom.
    - Facebook En Vivo, a Lead Presentation for Spanish speaking parents.
    - Instagram Live, Q&A about lead (137 viewers)
  - Virtual Lead Prevention Resource Fair via Zoom Event at National Park Elementary School in Gloucester County included a lead screening pilot program. Children were tested for lead. Southern NJ Perinatal Cooperative (SNJPC) and Gloucester County Health Department staff were at the school to assist the school nurse with the students being screened.
  - 2-hour Healthy Homes Training Series. CHES/MCHES credits were provided for those eligible to receive them. Staff also attended an outdoor flu clinic in Camden City to distribute lead testing information to parents.
  - *Rinsey Raccoon* handwashing e-book.

#### **4. Office for the Prevention of Developmental Disabilities (OPDD)**

The Office for Prevention of Developmental Disabilities is based in the Department of Human Services’ Division of Developmental Disabilities and works with the Council and its Task Forces to pursue a common charge - the prevention of intellectual/developmental disabilities in the State of New Jersey. One of the OPDD’s tasks is implementing, monitoring, and evaluating community prevention programs that receive support from its annual state appropriation.

#### **Office for the Prevention of Developmental Disabilities Grant Funding**

The OPDD funds agency projects that are intended to prevent intellectual/developmental disabilities. FY 21 was the second year of a three-year funding cycle. All of the OPDD funded projects were impacted by the COVID-19 pandemic and all employed strategies that were intended to adapt to this new working environment and ultimately reach their goals. Projects, scheduled to receive funding during fiscal years 2020 – 2022, are as follows:

- Statewide Parent Advocacy Network (SPAN) - \$184,975 per year  
 The overarching goal of *Empowering Women in Community Leadership for Healthier Families* project is to enhance state and community efforts to reduce the risk of preventable Intellectual and Developmental Disabilities (IDDs), specifically fetal alcohol syndrome (FAS)/fetal alcohol spectrum disorders (FASD) and those caused by lead poisoning. This will be accomplished by: a) providing peer support groups for diverse women of childbearing age, particularly those from underserved communities; and b) training women of childbearing age to be peer leaders who educate and advocate in their communities to reduce the risk of preventable IDD.

For the second year of this project (FY 21), the agency's reports document the activities and numbers of women trained in each location by type of training, language of training group and geographic region. As per the second year annual summary report, "participants noted increased knowledge in all seven of the program's key content areas, with a total average score that increased from 3.3 (before the training) to 4.5 (after the training) on a 5-point scale. Participants baseline knowledge ratings were slightly higher in Year One (M=3.7) which resulted in a larger overall increase in knowledge in Year Two (by 1.2 scale points) compared to Year One (0.9 scale points). Also in Year Two, leadership training participants rated their experience with the training as very positive, with average scores of 4.5 on a five-point scale. This finding was nearly identical to that reported in Year One. Participant feedback reported takeaways that included listening to the stories of other participants and learning how stories impact how to serve the community; learning how to conduct meetings and the key elements of leadership; the sense of community and support; learning about inclusion and representation; and learning about cultural competence."

The program evaluator further reported positive results tied to the project's central content areas of risks of alcohol use while pregnant; risks of drug use; lead poisoning prevention; social determinants of health; where to find help in their community; and how to advocate to improve their community. Additional items reported by participants included increased confidence and optimism about community involvement; sharing knowledge; cultural competence; group leadership; and organization skills.

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

The Smart Choices for a Healthy Life project utilizes the National Organization on Fetal Alcohol Syndrome (NOFAS) (now FASD United) K-12 Education and Prevention Curriculum in schools, after school programs, CBOs, and school districts serving target municipalities. The curriculum addresses many important topics for school-aged students beyond FASD and what can happen to human development when a pregnant woman drinks alcohol. It teaches about the overall effects that alcohol can have on the body, why some people who drink alcohol become addicted while others do not, that at any age each individual has strengths and weaknesses, and that it matters how you treat people.

The program modifications, due to the ongoing COVID-19 pandemic and begun in FY 20, continued into FY 21. Kindergarten – Second Grade children received in person education. Students in grades six – twelve received the curriculum virtually.

Program educators teaching the K – 2<sup>nd</sup> grade, Smart Choices for a Healthy Life curriculum, describe a strong response among children in their classrooms. Results from the classroom observation tool noted that children "demonstrated high levels of involvement and understanding of program content in the three key areas:



introduction to FAS; understanding people with differences, and respect for others, regardless of abilities.”

The grades six – twelve component of the program experienced two serious challenges to collecting evaluation data during Year Two. Prior to the Covid-19 epidemic, parental consent forms were developed, distributed and collected. The change to a virtual learning environment made matching these forms, with collected data, problematic. The program team resolved this issue by implementing an updated electronic consent process. However, the overall amount of evaluation data collected remained low relative to the total number of students who received the Smart Choices education. It is anticipated that the statewide return to in-person instruction in schools will resolve this issue.

A second reported challenge was a determination that the evaluation instrument, adapted from the evidence-based National Organization on Fetal Alcohol Syndrome (NOFAS) K-12 Education and Prevention Curriculum, was not challenging enough for the students. To address this issue, the team developed a new, more challenging pre-posttest instrument that was pilot tested during the fourth quarter. The new evaluation instrument appears to better assess knowledge attainment. The evaluator notes that “more than 85% of students in grades 9-12 significantly increased their knowledge of the program’s key content about the dangers of alcohol use before and during pregnancy and the importance of making healthy decisions about alcohol use and pregnancy.”

Social media was utilized to promote the mission of the project. Programming appeared on YouTube, Facebook and Instagram. Although the program evaluator describes the project’s social media work as successful, she notes that working with a social media consultant could benefit this aspect of the project.

- 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. These children may be at greater risk of Autism Spectrum Disorder (ASD). Children’s social communication development are evaluated through use of 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 are 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 an Early Intervention Program (EIP).

The project started enrolling subjects in January 2020 following research preparation activities. Due to COVID-19 restriction, including mandatory shut-down of the Rutgers--NJMS-PCCC program, the study activities were suspended between April-June 2020. Project activities resumed in August 2020. The volume of NJMS-PCCC patients was significantly below 2019 levels, between August and December 2020. Since January 2021, PCCC volume patient visits & services increased incrementally and are approximately at pre-COVID-19 levels. Due to COVID-19 restrictions, the research program adopted new strategies to continue activities. The agency reports the following additional benchmarks:

- To date, 373 families have been enrolled and screened for ASD using PDQ-1 and M-CHAT. The families were administered a total of 797 screeners. Children enrolled at younger ages (18-24 months) are screened multiple times at different ages per American Academy of Pediatrics (AAP) guidance.
- To date, 85 children (23%) of the enrolled subjects screened positive for ASD (considered at risk). All children with positive ASD screening have been referred to Mom2Mom for additional assistance/intervention. The number of positive (at risk) cases is higher than expected. A 23% identification rate suggests that the screener is identifying cases of ASD, but this can only be confirmed by tracking screened positive cases, over time.
- Mom2Mom peer counselors have contacted guardians of children who screened positive to assist in receiving EIP services and to facilitate referral to and evaluation by a developmental specialist for clinical assessment of ASD and/or other developmental disability. To date, Mom2Mom have completed 314 calls to 56 families that screened positive to provide additional support.
- Among the 85 screened positive children, 66 (78%) children have been referred or in the process of receiving early intervention services, and 52 (61%) children have been referred or in the process of receiving developmental evaluations.
- Additionally, as part of the project, all children are screened for lead. The project identified 20 cases with high lead levels (5%) of all children participating in the study, and among the screened positive children, 3 were identified with high lead levels (4%)
- The investigators have requested and received a report from PCCC clinic (EPIC electronic medical record system) to compare ASD screening between 1/1/2019 – 3/1/2019 and 1/1/2020-3/1/2020 to determine if ASD screening improved during the same period, after the start of the project. Comparison analysis is ongoing. Preliminary data suggest an estimated increase of 10-15% in screening at the NJMS-PCCC clinic. Additional analyses will determine if sociodemographic differences between families that enroll in the project and families that decline to enroll with the project are identified.
- Overall enrollment has been lower than expected. This was largely due to COVID-19 restrictions, including complete shut-down of the Pediatric CCC.
- The investigators have developed an alternative strategy for receiving remote (verbal) consent so that enrollment and NJMS-PCCC screening might continue through telemedicine operations/strategies. IRB approval of this modification

was granted in 2020 and now there is an additional venue for Autism evaluation of 18 and 24-month old children, in the Rutgers system.

- The investigators engaged two first year (NJMS) medical students in 2021, to promote ASD screening in the Newark region and to identify and recruit new participating sites for implementation of ASD universal screening, in the Newark region.

## **Appendix A**

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

9/23/2020

- Partnership Maternal Child Health Northern NJ  
Liliana Pinnete, Jessica Marino, Judy King

3/24/2021

- Maternal & Infant Outcomes During COVID-19  
Kathryn P. Aveni, DOH

6/23/2021

- What We Know & How We Move Forward - Cannabis Use & Pregnancy in NJ  
Damali Campbell-Oparaji, M.D.

## **Appendix B**

### **Governor's Council on the Prevention of Developmental Disabilities FY 2021 Membership**

#### **State of New Jersey Government Representatives**

Adam Bucon, LSW	Department of Human Services
Linda Barron, RN, MSN	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. Carol Ann Hogan, M.S. Ed.
7. William Holloway, Ph.D.
8. Martin Johnson
9. George Lambert, MD
10. Barbara May, RN, MPH
11. Michael McCormack, Ph.D., FACMG
12. Judith Morales, MSW, LCSW
13. Munir Nazir, MD
14. Beatriz Osterheld
15. Daniel Ranieri
16. Marlene Schwebel, JD,APN
17. Alyce M. Thomas, RD
18. Yvonne Wesley, RN, Ph.D.
19. Thomas Westover, MD
20. Jean Wiegner, CSNA
21. Leon Zimmerman
22. Ilise Zimmerman, MS

#### **Staff**

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