

Governor's Council on the Prevention of Developmental Disabilities



Annual Report for Fiscal Year 2023



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 2023

The Governor's Council on the Prevention of Developmental Disabilities (the 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 (IDDs) 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 IDD prevention programs in the state, and administers two standing committees in the service of its mission; the Fetal Alcohol Spectrum Disorders (FASD) and Other Perinatal Addictions Task Force, and the Interagency Task Force on the Prevention of Lead Poisoning. Without compensation, public members of the Council imbue this work with a high level of intensity, expertise, and dedication.

Governor's Council on the Prevention of Developmental Disabilities

Public Members:

Dorothy Angelini, MSN
Jeananne Arnone, RN, BS
Caroline Coffield, Ph.D.
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Carol Ann Hogan, M.S. Ed.
William Holloway, Ph.D.
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State Agencies:

New Jersey Department of Community Affairs, Commissioner Jacquelyn A. Suárez
Jennifer Underwood

New Jersey Department of Health, Commissioner Dr. Kaitlan Baston
Lisa Stout, BSN, RN

New Jersey Department of Human Services, Commissioner Sarah M. Adelman
Adam Bucon

New Jersey Department of State, Lt. Governor/Secretary of State Tahesha L. Way
Rowena Madden

New Jersey Department of Education, Acting Commissioner Kevin Dehmer
Kenneth Richards

New Jersey Department of Environmental Protection, Commissioner Shawn M. LaTourette
Gloria Post, Ph.D., DABT

Staff:

Office on Autism & Office for the Prevention of Developmental Disabilities,
Department of Human Services
Jonathan Sabin, LSW, Director

Fiscal Year 2023 Activities

With assistance from the OPDD, the Council met via online meeting platforms according to its quarterly schedule. This allowed the Council to continue its important work with funded projects commissioned by OPDD and to embrace its role of working with partners to maintain its advisory mission to the OPDD and DHS. The Council and OPDD examined many IDD 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 2023, the Council focused on the following activities:

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 relevant child development impacts 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. Throughout the year, several guest speakers presented information on matters affecting issues of health and support for pregnant women and child development.

Fetal Alcohol Syndrome and lead poisoning are matters of such concern to the Council, that the Council created two task forces to address the specific concerns associated with these issues; the New Jersey Task Force on Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions (FASD Task Force) and Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force).

With guidance from the FASD Task Force, the Council emphasized the importance of the "Advancing FASD Research, Prevention, and Services Act", which could greatly improve education and community engagement on FASD. They also focused on raising awareness among school and university students about FASD prevention.

Lead and its effect on NJ communities was a discussion topic at every meeting. The Lead Task Force helped the Council by reviewing community-centric approaches to lead reduction and brought to the Council's attention NJ Department of Health, State Health Assessment Data (NJSHAD) regarding childhood lead. Additional work being conducted by the NJ Department of Community Affairs and their lead assistance programs helped the Council better understand much of the lead poisoning prevention work that is currently funded by the state. Council members acknowledged increased attention to lead poisoning by news outlets and both federal and state governments.

Maternal Health is at the core of developmental disability prevention. Issues that hinder or prevent access to appropriate maternal health care for pregnant people, around New Jersey, were reviewed by the Council. Partners at the NJ Department of Health reviewed the latest Pregnancy Risk Assessment Monitoring System (PRAMS) with the Council. Discussion topics included racial/ethnic bias impacts on maternal health and methods to reduce disparities in maternity care. Additionally, Council members received follow up data regarding the impact of Covid-19 on maternal and infant outcomes.

Since New Jersey has decriminalized the possession of cannabis for personal use the Council remains cautious regarding the increased availability of cannabis products, and the veracity of information pertaining to cannabis and its impact on maternal/child health. The Council spent significant time and effort keeping itself apprised of current research on cannabis and its teratogenic impact on pregnancies.

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 FASD, and to promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

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, related to FASD. The FASDTF focused on increasing awareness in New Jersey about FASD and perinatal substance use disorders among the public and healthcare professionals. Additionally, FASDTF members continue to engage in vigorous discussions pertaining to cannabis legalization, its increased usage in NJ, and its potential impact on fetal development.

The FASDTF monitors the interests and activities of FASD United (formerly NOFAS). Task Force members participated in FASD United Policy Forums and were part of the FASD United efforts to advance the Federal FASD Respect Act (Advancing FASD Research, Services, and Prevention Act) and learned of the concerns of colleagues, nationally, pertaining to cannabis awareness and its possible impacts on a fetus.

Members of the FASDTF address a variety of matters important to maternal/child health and the prevention of developmental disabilities including updating and

promoting the FASDTF resource guidebook and website. Members reviewed New Jersey's ResourceNet system that is intended to help individuals and families find needed supports. Task Force members and their agencies promoted FASD Awareness Day/Month which started on September 9, 2022 via health fairs, school presentations, hospital presentations and social media activities.

Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force)

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 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 country's aging water delivery infrastructure, in addition to the hazards of lead paint, motivate the members of the Lead Task Force to reduce lead's dangerous footprint in NJ.

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.

In FY 2023, the Lead Task Force met in September and December 2022 and during March and June 2023. The Lead Task Force contemplated current lead issues affecting the State of New Jersey including:

- Investments in lead service line replacement;
- The implementation of P.L.2021, c.182. that requires lead paint inspections on certain residential rental property, including upon tenant turnover, and establishes a lead-based paint hazard education program. This new law also led to the change in the NJ Department of Health's (DOH) Blood Lead Reference value to 3.5 mcg/dL and above from its prior rate of 5 mcg/dL. The Blood Lead Reference value determines appropriate follow-up action by state and local government entities and their agency partners.

- The promotion of local activities through the Northern, Central and Southern Lead Coalitions, including events during National Childhood Lead Poisoning Prevention Week.
- Discussion on the difference between “lead safe” status and “lead free” status;
- Efforts to improve lead screenings and referral processes among health care providers/pediatricians;
- The NJ Department of Environmental Protection’s Potential Lead Exposure Mapping tool (PLEM) intended to help local health officers, community groups and the public better identify older homes in New Jersey that may contain lead paint;
- The use of biomonitoring tools to measure chemical exposure in humans.

Three subgroups were formed within the Task Force including the Screening of Children subgroup that explored:

- strategies for engaging doctors, particularly family physicians and pediatricians, to underscore the significance of lead screening and the role of healthcare in this process;
- the feasibility of offering Continuing Medical Education (CME) courses to train nurses on the importance and procedures of lead screening;
- barriers to accessing lead screening services through commercial labs including identified parental time and transportation; and
- the general challenges of raising awareness among both parents and healthcare providers about the importance of lead screening and emphasized the need for comprehensive investment in inspection, remediation, case management, and relocation services alongside increased screening efforts.

The Lead Task Force’s Data Reporting subgroup addressed topics including:

- the ongoing utilization of Potential Lead Exposure Mapping (PLEM) and the accessibility of lead data for home renters;
- the availability of loans for renters to cover expenses related to unexpected costs associated with lead abatement efforts and lead service line remediation;
- the collaboration between the Department of Children and Families (DCF) and the Water Infrastructure Improvements for the Nation Act (WIIN Act) in conducting comprehensive testing for lead in drinking water;
- the potential of using mapping tools to track data, which would be beneficial for risk assessors and agencies involved in lead remediation and abatement work; and
- the role of advocates in improving data access and reporting in New Jersey.

The Early Intervention subgroup addressed issues including:

- the concept of resource sharing, including the possibility of sharing the PLEM tool with Sustainable Jersey;
- the importance of educating healthcare providers about the necessity of follow-up venous testing rather than relying solely on capillary testing;
- the potential of utilizing outreach models through preschools and daycares to reach families and provide education on lead exposure prevention; and
- organizing lead education events and screenings at schools.

The Lead Task Force heard from speakers on subjects intended to assist them with their work. Speakers included:

- Department of Community Affairs Lead Assistance Programs – Xin Li & Angie Armand
- Childhood Lead Prevention Project ECHO – Harriet Lazarus
- Green & Healthy Homes Initiative (GHHI) – Wes Stewart
- New Jersey Residential Lead Hazard Regulations Common Issues, Questions, Misconceptions – Michael Kogut
- NJ Biomonitoring and Exposure Assessment Program – Eric Bind

Office for the Prevention of Developmental Disabilities FY 2023 Grant Funding

OPDD funds agency projects that are intended to prevent IDD. FY 2023 was the first year of a three-year funding cycle.

Partnership for Maternal and Child Health of Northern NJ (PMCHNNJ)

Award: \$185,000 per year

The PMCHNNJ is implementing the Smart Choices for Healthy Living Project. FASD United (formerly National Organization on Fetal Alcohol Syndrome (NOFAS)) developed a K-12 FASD Education and Prevention curriculum. The Smart Choices for Healthy Living Project utilizes this curriculum with K-12 youths that live in Bergen, Essex, Hudson, Morris, Passaic, Sussex and Warren counties in order to prevent IDD by reducing the incidence of FASD. PMCHNNJ also provides screening and early intervention education to school nurses and FASD prevention education to college students.

The Smart Choices team reports that they were able to utilize previous connections and create new connections to schedule presentations with schools throughout northern New Jersey in the first year of this new grant cycle. Presentations were offered virtually and in person, in order to eliminate barriers preventing them from bringing the presentations to schools. The team reports educating 5,026 students, 66 school nurses and 347 college students from their target populations this year.

The Smart Choices team continued to use evaluation tools for the K-12 programs developed during previously funded quarters.

New Jersey Chapter of the American Academy of Pediatrics (NJ AAP)

Award: \$185,000 per year

The NJ AAP is implementing the Childhood Lead Poisoning Education ECHO project. This program is educating primary care clinicians and community stakeholders about the importance of prevention, early identification and referral of children with elevated blood lead levels. The program also educates pediatric providers about the Department of Community Affairs (DCA) remediation program so that they can refer families to receive free home inspections to identify potential sources of lead. The two-tiered program utilizes the Project ECHO model of virtual case based bi-directional education to ensure that a wide audience of diverse clinical and community stakeholders can participate.

In the first program cohort, NJ AAP reports that 34 providers from 16 practices have enrolled in the program and that participating practices have submitted 6 cycles of data and 5 cycles of case presentations. The program notes monthly data submissions to analyze outcomes (both aggregate and individual chart level data). Ten practices have submitted all six cycles of data (Baseline, Cycle 1, Cycle 2, Cycle 3, Cycle 4, and Cycle 5) via the AAP's Quality Improvement Data Aggregator (QIDA). Data is analyzed monthly. The aggregate run charts are shared on monthly ECHO sessions. Participants also submit monthly case presentations which were either a success, a challenge, or a case for which they are requesting coaching from the hub leaders. In addition to monthly data and case presentation submissions, participants were asked to submit a post-session evaluation following the conclusion of ECHO Session 3, 4, and 5. Sessions were rated highly and received positive feedback.

Parent Advocacy Network (SPAN)

Award: \$185,000 per year

Leaders Empowered as Advocates with Dignity (LEAD) focuses on maternal, paternal and children's health as well as mental health by providing leadership training and education, and community engagement for women and men of childbearing age to prevent IDD, specifically Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder (FAS/FASD). The LEAD project addresses social determinants of health including poverty, language barriers, Adverse Childhood Experiences (ACEs), societal and environmental stress, access to service systems, immigration, language barriers, and others that influence issues such as smoking, substance use, and nutrition.

The SPAN LEAD project reports that 22 individuals participated in the LEAD leadership training from the Southern New Jersey counties of Burlington, Camden,

Ocean, and Atlantic, as well as the Northern/Central counties of Essex and Mercer. According to data from these participants, the leadership training was successful at increasing participant knowledge of the learning objectives, with 91% reporting higher levels of knowledge after the training compared to before, thus meeting the program's target benchmark of 79%.

During Year 1, project staff noted that data show a significant increase in mean knowledge ratings from before to after the session. In addition, participants provided feedback indicating that they will use what they learned including sharing session resources with friends and family, using breathing techniques for stress relief, listening skills, and adding new self-care strategies to their daily routine. Additionally, staff commented that focus group participants revealed that people in communities face many challenges to emotional well-being including stress, depression, loss and grief, joblessness, work-family balance, domestic violence, drugs, gambling, discrimination/racism, exploitation of immigrants, rising cost of living, and difficulty meeting basic needs. Further, some groups report experiencing more challenges to their emotional well-being, such as people with disabilities, older adults, youth, children, people with language barriers, immigrants; and people who identify as Black/African American, Hispanic, Latino, or LGBTQ.

Appendix A

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

9/28/2022

- Smart Choices Project/Partnership for Maternal & Child Health of Northern NJ
Kelly Dietrich & Sarah Muller-Robbins
- Annual Ethics Briefing
Kya Saunders

12/21/2023

- NJ Department of Health Project W.
Shaila Montero
- AIM Patient Safety Bundles
Dr. Thomas Westover

3/22/2023

- SPAN - Empowering Women in Community Leadership for Healthier Families
Nicole Pratt

6/28/2023

- NJ Department of Health Childhood Lead Exposure Report
Siobhan Pappas