Deborah Munroe Noonan Memorial Research Fund 2022 Award Recipients

• Eileen Crehan, Ph.D. Assistant Professor Tufts University

"IEP Coding to Inform Equity Advocacy Efforts"

This project aims to better understand how language spoken at home and other sociodemographic factors (e.g., race, gender, SES) impact IEP services for autistic children. By collecting IEPs and questionnaires from parents of children ages 3-10 living in Massachusetts, we will be able to characterize how these sociodemographic factors impact the types and amounts of services included in IEPs, the quality of the written goals, parental satisfaction with services, and qualitative experiences around the development and maintenance of an IEP. Study materials will be available in four languages (English, Spanish, Portuguese, Cantonese). The IEPs will be coded for content and quality of goals using a pre-established coding approach. Quantitative analysis will identify educational service gaps and qualitative responses both from the content of the IEP and from the parent questionnaires will provide important context and examples of supports that were useful or challenging for parents. Results will inform the development and dissemination of advocacy materials in all four languages. This work will be conducted in collaboration with our Community Advisory Board to help ensure that findings and advocacy materials are meeting the true needs of families in Massachusetts navigating the special education system.

• Yarden Fraiman, M.D., M.P.H.

Instructor

Beth Israel Deaconess Medical Center / Harvard Medical School

"Identifying Neighborhood Drivers of Racial and Ethnic Disparities Along the Early Intervention (EI) Care Cascade for Very Preterm Infants in Massachusetts"

Very preterm infants (VPT) have an increased risk of neurodevelopmental, language, learning, and functional impairments. In Massachusetts, all VPTs are eligible to receive Early Intervention (EI) services, via the federally mandated Individuals with Disability Education Act after successful navigation of the "EI Care Cascade" (EI-CC). EI improves cognitive, behavioral, functional, and social outcomes for VPT, but racial and ethnic disparities exist leading to an inequitable burden of chronic disabilities.

Race is a social construct and disparities are due to structural, institutional, interpersonal, and internalized racism. Identifying structural racism embedded in environments can be used to identify targets for population-level interventions.

Neighborhoods are modifiable environmental contexts that shape pediatric health and are a source of structural racism due to historical de jure and present-day de facto segregation and divestment.

In this proposal, we will characterize the neighborhood-based resources that support successful navigation of the EI-CC in order to identify population-level, neighborhood-based targets for novel interventions to increase equitable access to EI.

Study Design: Secondary multilevel analysis of the PELL dataset of the Massachusetts Department of Public Health

Aims:

- 1) Characterize racial and ethnic disparities along the EI-CC in MA.
- 2) Quantify the role of geographical residence, specifically EI Catchment Area and neighborhood, on racial and ethnic disparities in the EI-CC.
- 3) Identify the modifiable neighborhood-based opportunities and EI catchment area characteristics that promote EI-CC equity.

The results of the study will inform interventions to reduce the inequitable burden of chronic conditions and disabilities among children in Massachusetts.

This innovative proposal uses novel multilevel approaches nesting individuals within neighborhoods and EI catchment areas, to elucidate the role of neighborhoods in sustaining or dismantling inequity. Additionally, it focuses on neighborhood-based resources, not vulnerabilities, that can be integrated into neighborhoods through population-based interventions and thereby improve neighborhoods and equity for all children in Massachusetts.

• Jocelyn Kuhn, Ph.D.

Assistant Professor of Pediatrics

Boston Medical Center

"Testing the Efficacy of an Adapted Family-Centered Autism Transition Intervention in a Safety Net Hospital Setting"

Autistic adults, especially those from low-resource communities, experience poorer quality of life, physical and mental health, economic self-sufficiency, independent living, and educational outcomes than their neurotypical counterparts. The transition to adulthood between the ages of 14 and 23 represents a critical time to disrupt these inequities and set autistic youth on a trajectory for improved outcomes. Our research team previously developed and tested an autism transition-to-adulthood intervention called Transitioning Together, which is based on an evidence-based multi-family group psychoeducation model and has demonstrated efficacy in improving outcomes for both youth (e.g., social and behavioral functioning, employment) and their parents/guardians (e.g., well-being, coping skills). Our widescale implementation study of this intervention across three states found that lower-resource service settings where disproportionately more racial and ethnic minority families are served struggled to adopt this intervention. Thus, without further adaptation, dissemination of the intervention in its original form risks unintentionally widening existing racial, ethnic, and socioeconomic disparities among autistic people. Such disparities are known to pervade quality of life, health and well-being, employment, and education across the life course. To address these prior study findings, we recently adapted Transitioning Together to improve its feasibility, accessibility, and cultural responsiveness in low-resource service settings. Examples of adaptations included consolidating program content into fewer, longer group sessions, and culturally adapting content for Spanish-speaking families. Families who participated in our small pilot test of this adapted version of the Transitioning Together program reported high satisfaction with the program and strong social validity. The effectiveness of the adapted version has not yet been tested. In the proposed project, we seek to test the effectiveness of this adapted version of Transitioning Together within the Boston Medical Center network, where predominantly low-income communities across Greater Boston, including families who represent a rich diversity of racial and ethnic backgrounds, are served.

• Andre Maharaj, Ph.D.

Graduate Program Director of Applied Behavior Analysis; Senior Research Associate *University of Massachusetts Boston*

"Stronger Together - The Benefits of Inclusion for Treating Children with Externalizing Behavior Problems"

The purpose of the project is to develop and assess an inclusive summer intervention program for children with externalizing behavior problems (EBPs) from low-income minority families in Boston. The goal is to scaffold positive developmental trajectories and ameliorate later functional limitations in major life activities. The intervention includes behavior modification components, a social-emotional and self-regulation curriculum, an academic curriculum, and a parent training program. It will be implemented in an inclusive recreational setting with typically developing peers to foster social competence and facilitate generalization of peer relationship skills back to the typical classroom.

The specific aims are to: (1) Integrate the evidence-based Summer Treatment Program (STP; Pelham et al., 2010) into Camp Shriver, an evidence-based inclusive recreational summer camp for children with and without disabilities (Siperstein et al., 2022), (2) Assess the feasibility of implementing the melded intervention in Year 1 and use findings to inform modifications for replication in Year 2, (3) Evaluate the effectiveness of the adapted intervention, and (4) Provide initial data to be used in applications for funding subsequent evaluation studies and scaling up of the intervention.

The Demonstration Project will utilize a mixed design with replication. The STP will be modified to fit into the schedule and inclusive setting of Camp Shriver. Staff will be recruited and trained using the modified program. Families of children with and without EBPs exiting the first grade will be recruited from the Boston Public School system and pediatric psychiatric practices each year, for two years. The first cohort will participate in the adapted intervention in Year 1, and structural, process and outcome measures will be obtained. Using the information from Year 1 (e.g., feasibility, parent satisfaction, child outcome measures), the intervention will be modified and fine-tuned for replication and evaluation with a second cohort in Year 2.

• Pam Nourse, M.B.A.

Executive Director
Federation for Children with Special Needs

"Capacity Building in Greater Boston's Vietnamese Community"

Research shows that effective family engagement improves health and educational outcomes for children and youth. In this project FCSN will increase capacity for family engagement among families and professionals through a community asset mapping process and creation of relevant resources and trainings. The focus of the project is to address disparities experienced by the families with children with special health care needs in three targeted Vietnamese communities in Greater Boston. Priorities for family engagement capacity building will be set with the community through a community asset mapping process. The materials, resources, and training will be cocreated with the community to address these priorities. For example, the community may find that greater knowledge of how to access resources at local community health centers is a priority, and FCSN will correspondingly develop the relevant materials and training. Culturally relevant resources will be tailored for both Vietnamese families and for the education and health care providers who work with the community. Project staff will include a Vietnamese Outreach Specialist; four cultural brokers who are members of the targeted communities will work in stipend positions as well. Outcomes will be measured through multiple surveys and trainings and resources will be adjusted throughout the project to better meet the needs of the Vietnamese community, based on evaluative responses.