

Deborah Munroe Noonan Memorial Research Fund 2018 Award Recipients

Zubair Ahmed, Ph.D.

Professor of Otorhinolaryngology and Ophthalmology

system, resulting in late gross motor milestones and poor balance. These children also have retinitis pigmentosa with symptoms that develop as early as their toddler years, with night blindness followed by increasingly narrow tunnel vision progressing to total blindness during adulthood. To date, no therapy is available to preserve vision in USH subjects. However, recent success and FDA approval for gene replacement for Leber Congenital Amaurosis (LCA), has opened the door for other genetic causes of RP, including USH1. Gene replacement holds the potential to halt and possibly even reverse vision loss that has already occurred, thus sparing affected children a future of blindness. A grant from the Sara Elizabeth O'Brien Trust would provide the opportunity for children with USH type 1F to reap the same benefits as those with LCA.

Here, we will evaluate the efficacy and efficiency of virus based PCDH15 gene, responsible for USH1F, delivery in Pcdh15 knockin (KI) mouse model to restore vision. We will take advantage of our highly efficient, synthetic, adeno-associated Anc80L65 virus for targeting retinal sensory cells in KI mice. Our exciting preliminary data indicate that Pcdh15KI/KI mice have significantly attenuated electroretinogram a- and b-waves amplitudes at postnatal day 30. We will generate various combination of PCDH15 gene constructs and will test their functional efficiency in mammalian cell cultures followed by generation of viral particles. Validated viral particles will be used for in vivo gene delivery via sub-retinal injections in control and Pcdh15KI/KI mice. Effect on retinal development and functions will be evaluated using physiological and histological examinations. We expect that vision function will be significantly improved with the gene delivery both in young and adult mice.

Marji Erickson Warfield, Ph.D.

Sara Folta, Ph.D.

Associate Professor

Tufts University

“Exploring Leisure Time Use and Impact on Health and Well-Being among Transition-Age Youth with Autism Spectrum Disorder”

The transition to adulthood has emerged as an important focus for youth with ASD. Navigating the transition period from adolescence to adulthood is difficult for many young people, but those with ASD experience additional challenges in social, vocational, independent living, and emotional life domains. Moreover, recent research has shown that quality of life (QOL) is lower for transition-age youth with ASD than their typically developing counterparts. There is evidence for the link between leisure time pursuits and overall subjective well-being and QOL in the general population. Leisure time activities provide individuals with opportunities to build relationships, experience positive emotions, and acquire new knowledge and skills. However, the linkage between leisure time pursuits and QOL has been studied in only a limited way in transition-age youth with ASD, and in the majority of these studies parents responded on behalf of their offspring. We aim to 1) use participant-driven photo-elicitation (PDPE), a method of qualitative data collection in which participants take photographs to document their reality, followed by an in-depth interview, to gain insight into leisure time use by youth with ASD; 2) explore how leisure-time activities may be related to well-being, in how they do or do not help meet the basic psychological needs of competence, autonomy, and relatedness; and 3) gain an understanding of the types of activities chosen, reasons for engaging in them, perceived benefits, and challenges. Our findings will provide preliminary data to develop future research to explore the association between leisure time activities and health and well-being, as well as the development of interventions to assist in the use

Jennifer Green, Ph.D.

Associate Professor of Education

Boston University

“Identifying Factors That Contribute To Disparities In Adolescent Mental Health Service Access In School”

This project aims to identify specific school resources that contribute to reducing disparities in access to adolescent mental health services. Prior research has identified some individual-

Ovsanna Leyfer, Ph.D.

Research Assistant Professor

Boston University

“Intensive Cognitive-Behavioral Therapy for Anxiety Disorders in Adolescents”

Anxiety disorders (ADs) are a prevalent and chronic condition, affecting approximately 32% of adolescents. ADs are associated with high levels of impairment in functioning as well as substance abuse and other mental health issues. Cognitive-behavioral treatment (CBT) for ADs in youth has demonstrated efficacy. However, fewer than 20% of adolescents receive services for anxiety-related problems. Some of the barriers include a lack of access to services, and difficulties scheduling multiple weekly sessions over extensive period of time. There is a critical need to find innovative ways to reduce these barriers in order to decrease impairment and improve youth’s quality of life. One possibility is intensive treatment, i.e. treatment delivered in several hour long sessions over the course of one week.

Such treatment can provide more immediate relief for families, faster return to daily activities for youth, increase accessibility to treatment, reduce the burden of travel and homework, and it can be conducted at convenient times for the family, such as a school break. Despite these advantages, there is only a handful of intensive protocols developed for youth with ADs. No protocols have targeted the entire spectrum of often comorbid ADs in adolescents, yet the studies of the intensive treatment for panic disorder demonstrated a significant decrease in the rates of other comorbid ADs in the participants (in addition to panic). This project aims to develop an intensive cognitive behavioral treatment program for youth aged 11-17 with ANY anxiety disorder and to conduct a multiple baseline trial with 15 adolescents randomized to 2, 3, and 4-week baseline. The treatment will be evaluated in terms of its feasibility, acceptability, patient satisfaction and engagement, and youth and family perceptions of barriers/enhancers to the sustainability of the intervention. Potential indicators of efficacy and mechanisms of change will be examined.

Ariel Schwartz, Ph.D.

Postdoctoral Fellow

Boston University

“Development and Feasibility Evaluation of a Socially Valid Peer Mentoring Intervention for Young Adults with Intellectual/Developmental Disabilities and Mental Health Conditions”

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**Deborah Munroe Noonan Memorial Research Fund
2019 Award Recipients**

Cheri Blauwet, M.D.

Susanne Hay, M.D.

Instructor in Pediatrics

Beth Israel Deaconess Medical Center / Harvard Medical School

“Systemic Corticosteroids For The Prevention And Treatment Of Bronchopulmonary Dysplasia—A Network Meta-Analysis”

Bronchopulmonary dysplasia (BPD) remains a major cause of neonatal morbidity, affecting 40% of very low birth weight (VLBW) infants born in the United States. Affected infants are at high risk of long-term pulmonary complications and neurodevelopmental sequelae. Systemic corticosteroids have proven efficacious in the prevention and treatment of BPD. Shortly after the initial trials, over 30% of VLBW infants were treated with postnatal corticosteroids. However, in follow-up studies, serious long-term complications were reported, including elevated rates of cerebral palsy. Use of postnatal steroids subsequently fell to 8% of VLBW infants, and the frequency of trials evaluating postnatal steroids also decreased. Concerningly, data are lacking on the optimal steroid regimen. Two different systemic steroids, dexamethasone and hydrocortisone, are commonly used; but their relative safety and efficacy is unknown, as the two treatments have not been studied head-to-head. To further understand the need for these trials and what evidence we can obtain from the many existing trials, we propose a network meta-analysis (NMA) with indirect comparisons of extant data.

This proposal is significant in several ways. First, as trial data within similar patient populations exist comparing dexamethasone and hydrocortisone separately to placebo, we can build indirect comparisons between these treatments with the use of network meta-analysis. This approach will provide further precision of effect estimates and a greater understanding of optimal therapy for this fragile population without subjecting infants and their families to further clinical trials and without dedicating limited research resources to costly, large RCTs. While RCTs remain the gold standard, this analysis could inform future, more definitive trials, thereby increasing their efficiency. Second, as network meta-analysis remains a relatively new tool and one as yet infrequently used in neonatology, our work can help pave the way for the understanding and performance of further network meta-analyses in the field.

Mary Hughes, Ph.D.

Nurse Scientist

Franciscan Hospital for Children

“Emergency Preparedness: Parent Training For Children With Medical Complexity Using Simulation Learning”

Children with medical complexity often require life-supporting artificial airways or life-sustaining medications administered through enteral tubes. Current standard of teaching provides parents with skills to perform routine tasks but a frightening dilemma faced by parents is when tasks change from routine to emergent. Simulation learning (SL) allows for practice of skills in a “real life” setting to support true readiness for emergency response. SL allows parents to enhance their knowledge, practice the skills and build their confidence. Documented use of SL with parents is limited; results, however, are promising. This demonstration project will result in a valid, reproducible SL intervention and evaluate knowledge, skills and confidence of parents for emergency responses at home for their children with medical complexity.

This 2-year project includes 4 phases: Phase 1 will be development of SL space emulating the home of a child with medical complexity. Nursing and Respiratory staff will be trained as simulation instructors and with simulation experts design scenarios of life threatening situations using relevant literature and site visits. Phase 2 will encompass piloting the SL space and scenarios with five parent pairs prior to hospital discharge. Validated scales pre/post hospital discharge will assess SL efficacy. Phone interviews will explore home emergencies and hospital readmissions at 24 hours and 1-month post-discharge. Scenarios will be revised and refined based on feedback from parents, SL instructors and experts. Phase 3 includes retriial and evaluation with 6 additional parent pairs (including non-English speaking). Phase 4 will be devoted to final evaluation. This intervention will improve caregiver preparedness for possible home emergencies and be a model for emergency preparedness for parents caring for children with medical complexity. We seek to enhance the quality of life for children with medically complexity by improving parents’ knowledge, skills and confidence to respond effectively to life-threatening emergencies at home.

Deirdre Logan, Ph.D.
Assistant Professor
Boston Children's Hospital

“Ready for Change: A Telehealth, Motivation Enhancement Prehabilitation Training to Increase Engagement in Children and Families Entering Intensive Interdisciplinary Pain Rehabilitation”

Readiness to change, or willingness to engage in a self-management approach to chronic pain and disability, is the most powerful predictor of children's success in intensive pediatric pain rehabilitation. Motivational Enhancement Therapy (MET) is an approach that has been effective in increasing readiness to change and treatment engagement for other behaviorally-oriented health interventions. However, MET has never been systemically employed in the context of treating pediatric chronic pain and disability.

This demonstration project seeks to test the effects of a novel telehealth intervention using motivation enhancement therapy to improve patient and parent engagement in, and outcomes of, an intensive interdisciplinary day hospital program for children with complex chronic pain conditions and associated disability, the Pediatric Pain Rehabilitation Center (PPRC). The intervention, PPRC-Prep, is a 4 week MET-based telehealth intervention that will be offered to famer -0.8 (a2 (h)-2.52.2 (t)-5.i2 .7 ((a)-0.9 8 (t)-5.(t)0.8 (h

Lotfi Merabet, Ph.D., M.P.H.

Director, Laboratory for Visual Neuroplasticity, Associate Professor of Ophthalmology
Massachusetts Eye and Ear Infirmary

“Characterizing Functional Visual Processing In Cerebral Compared to Ocular Visual Impairment”

Cerebral (cortical) visual impairment (CVI) is the leading cause of congenital visual impairment in the United States. There remain alarming gaps in our understanding of how developmental brain damage relates to visual perceptual deficits in CVI and furthermore, how these deficits differ from individuals with ocular based visual impairment. Standard ophthalmic clinical assessments fail to fully characterize functional deficits due to their lack of ecological validity. Thus, in the absence of an ocular abnormality, clinicians may dismiss visual perceptual complaints and many individuals with CVI remain undiagnosed. To address this unmet need, we have developed a novel virtual reality (VR) based testing platform to assess visual spatial processing abilities in tasks that approach real world situations. The objective of the proposed research is to develop a novel assessment method for functional vision performance and investigate the neurophysiological basis of these processing deficits in CVI. We will carry out psychophysical behavioral testing using a VR visual search task (the “virtual toy box”) combined with a multimodal neuroimaging study to characterize white matter structural integrity of key visual processing pathways and brain network activation (using diffusion based MRI and EEG respectively). Indices of behavioral performance and neuroimaging outcomes will be compared to age matched individuals with ocular based impairment and neurotypical controls. Our central hypothesis is that CVI participants will show a greater impairment in performance as a function of increasing visual task demands. Furthermore, these deficits will be associated with the maldevelopment of key visual processing pathways and impaired activation of brain networks implicated in higher order visual perception. Uncovering brain-behavioral associations in the case of CVI represents a crucial step in establishing a neurorehabilitative framework specifically designed for the care of these children as well as the creation of new adaptive tools and strategies for an individual’s specific needs.

Deborah Munroe Noonan Memorial Research Fund
2020 Award Recipients

Gary Bedell, Ph.D.
Professor

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Meg Stone, M.A., M.P.H.
IMPACT Executive Director
Triangle, Inc.

"Sexual Assault Resistance for Teens and Young Adults with Intellectual Disabilities"

The purpose of this demonstration project is to reduce sexual assault victimization among teens with intellectual disabilities. Following a Stage IA treatment development methodology, research activities will refine and evaluate the feasibility, acceptability, and preliminary efficacy of IMPACT:Ability+, a sexual assault resistance program for

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Julie White, M.S.

Director, Continuing Medical Education

Boston University

“Boosting Capacity to Screen and Care for Underserved Children with Autism Spectrum Disorders Through a Community-based, Interprofessional Training Program for Pediatric Care Providers”

The long-term goal of this proposed project is to improve the developmental outcomes of underserved Boston-area children with autism spectrum disorders (ASD). Toward this goal, we will advance these specific aims:

- 1) train an interprofessional group of Boston area community-based pediatric providers in screening, making appropriate referrals to specialists for diagnostic certainty, and providing ongoing care for children at risk and with of ASD.
- 2) evaluate effectiveness of the ECHO model in building capacity for appropriate, timely ASD diagnoses, referrals and services in an urban, safety net patient population.

Our target population are children in the Boston University School of Medicine/Boston Medical Center (BUSM/BMC) community health centers system with ASD who struggle with social communication and behaviors that impact their development. The lifelong impact of ASD, particularly if not treated early, can be pervasive throughout all realms of development and have significant impact on lifelong capacity of both the child and the family. Our objectives are to develop, implement, and evaluate the ECHO model of provider training by establishing a BUSM/BMC ECHO Autism Community of Practice among the BMC Division of Developmental and Behavioral Pediatric

Deborah Munroe Noonan Memorial Research Fund

Aviva Must, Ph.D.

Dean, Public Health & Professional Degree Programs

Tufts University

"GamerFit mHealth/Telehealth Lifestyle Intervention for Youth with Autism Spectrum Disorder"

Health disparities, particularly chronic disease risk, faced by youth with autism spectrum disorder (ASD) are rooted in a variety of early and persistent unhealthy behavioral patterns, including inadequate physical activity (PA), excessive screen time, poor diet and disrupted sleep. Extensive research documents associations between

Jaimie Timmons, M.S.W.

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

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

Deborah Munroe Noonan Memorial Research Fund 2023 Award Recipients

Abbey Eisenhower, Ph.D.

Assistant Professor

University Of Massachusetts Foundation

“Smooth Sailing In Early Childhood: A Relationship-Based Program For Improving Child-Educator Relationships And Minimizing Exclusion For Autistic And Neurodivergent Children”

Key Words: Autism, Early childhood education, Professional development, Child-educator relationships, Child-care and preschool, Neurodiversity affirming, Expulsion prevention

In the proposed research, we aim to develop an autism-focused teacher training program for early childhood educators (ECEs). With the diagnosed prevalence of autism increasing, one in every 36 children now has a diagnosis of autism.

Unfortunately, early childhood settings are not consistently inclusive of autistic and neurodivergent children, with one out of six autistic children expelled or dismissed from preschool or child-care. ECEs can serve as catalysts in ensuring positive, inclusive early school experiences

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Ovsanna Leyfer, Ph.D.

Research Assistant Professor

Boston University

“Increasing Access, Decreasing Anxiety: A Pilot Randomized Trial of a One Week Telehealth-Delivered Treatment Program for Adolescents”

Key Words: Anxiety Disorders, Adolescents, Mental Health, Intervention, Telehealth, Access to Treatment

Anxiety disorders are one of the most common psychiatric conditions in youth, and they are associated with high levels of impairment. Cognitive-behavioral therapy (CBT) has been found efficacious for their treatment. Howeund,ffth