

Deborah Munroe Noonan Memorial Research Fund 2018 Award Recipients

- **Zubair Ahmed, Ph.D.**

Professor of Otorhinolaryngology and Ophthalmology
University of Maryland Baltimore

“Gene Delivery To Prevent Vision Loss In USH1F Animal Model”

Usher syndrome (USH) is the leading cause of inherited deaf-blindness. Type 1 is the most severe, with affected children born profoundly deaf with an impaired vestibular 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.

- **Ilhom Akobirshoev, Ph.D., M.A.**

Research Scientist

Brandeis University

“Understanding the Health Care Needs and Experiences of Boston Children with Special Health Care Needs”

Evidence shows that children with special health care needs (SHCN) experience significantly worse health care than their typically developing peers, which is a major public health problem. However, most health care research has focused on child population representative at the national level. Our study will break new ground by understanding, from the parents' perspectives, their children's health care access, service utilization, quality, and disparities on a representative sample of children in Boston. Namely, we will identify the extent and determinants of disparities in health care access, service utilization and quality of Boston children with and without SHCN. We will use the 2012 Boston Survey of Children's Health, a groundbreaking, representative study of the health and well-being of children in Boston. We will model logistic and multinomial logistic regressions to assess health care access, service utilization, and quality for 399 children with SHCN and 1,701 children without SHCN. We will also assess these outcomes for children with SHCN stratified by select risk factors including minority race/ethnicity; non-English language spoken at home, being foreign-born, low-income status, parent(s) with no high school education, with insurance gap, and living a high-risk neighborhood.

Understanding the health care needs and experiences of Boston children with disabilities is likely to yield highly relevant information to inform policymakers and clinicians about the needs of children with disabilities and their families. Therefore, our findings will contribute to generating new knowledge that can help this highly vulnerable population and inform the development and testing of specific, targeted policy and practice interventions to reduce disparities and promote the functioning and well-being of Boston children disabilities.

- **Marji Erickson Warfield, Ph.D.**
Senior Scientist and Lecturer
Brandeis University

“Assessing Shared Living As A Residential Option for Youth Transitioning to Adult Services”

States are under mounting pressure to meet the needs of the growing population of youth with disabilities transitioning into the adult service system, serve newly eligible youth with autism spectrum disorders, and respond to mandates to implement service delivery approaches that maximize inclusion and community integration; all with limited resources. While research into transition from school to work and from pediatric to adult health care has generated information to guide service delivery, there has been little investigation of the transition of youth and young adults into more independent living opportunities. While most transition-age youth continue to live with their families after exiting the school system, a sizeable subgroup are eligible for residential services and often desire, and are capable of, managing more independent and self-directed living options.

Although historically, Massachusetts has allocated most of its residential funding for transition-aged youth to group homes, the state has embarked on a campaign to increase the use of the Shared Living (SL) Support Model where an individual with disabilities lives in a care provider’s home. In addition to evidence that independent living is less costly than group homes, SL is also seen as a residential model that offers youth a voice in choosing how they live and with whom, increases community inclusion and fosters interdependent friendships. There is a pressing need for research to assess the extent to which SL meets these expectations and whether this model works for youth.

The proposed study will (1) gain an in-depth understanding of the implementation and operation of SL opportunities among youth transitioning to adult services; and (2) assess the ways in which SL must evolve in the future. The results will generate recommendations for improving and expanding SL opportunities and for suggesting how SL can increase community participation and friendship formation among youth with disabilities

- **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 of leisure time that optimize health and well-being among transition-age youth with ASD.

- **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-level factors associated with lower likelihood of accessing mental health services, including identifying as non-Latino/a Black, and LGBTQ. Less is known about school factors associated with mental health service use. Limited research on this topic has suggested that improved school mental health resources (like screening and early identification efforts) are associated with increased use of mental health services, but more research is needed to assess how school resources might be related to service use disparities. Understanding school factors that increase youth access to needed mental health services, particularly for youth who are traditionally under-served, could contribute to determining policy levers for improving youth mental health service access. The current study addresses this long-term objective by: (1) identifying individual-level disparities in mental health service access, (2) identifying school resources associated with mental health services access, and (3) determining which school resources are associated with decreased disparities in mental health service access for traditionally under-served youth. This study will use data from the 2018 MetroWest Adolescent Health Survey, a biennial census survey of over 40,000 middle and high school students in 25 communities in the Massachusetts MetroWest region. In addition, we will collect new interview and survey data from school and district administrators on school mental health resources, such as the provision of preventative services and the availability of school and community-based mental health providers. Multi-level data analysis will identify individual- and school-level factors associated with mental health service use. We will construct interaction terms to examine whether school resources are associated with decreased disparities. Results have the potential to inform school mental health services planning.

- **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”

Young adults with intellectual/developmental disabilities (IDD) and co-occurring mental health (MH) conditions are at heightened risk for health and quality of life disparities, such as decreased community participation. Barriers to services to reduce these disparities include lack of professional knowledge about providing care for this population, long waitlists, and lack of services accessible via public transportation. Peer-delivered interventions, such as peer mentoring, may be one solution to these barriers. Peer mentoring, in which individuals with similar diagnoses are trained to provide support and/or deliver interventions, is considered a best practice in mental health intervention and consistently promotes positive outcomes for individuals with IDD. However, there are no such interventions designed specifically for the needs of young adults with IDD and co-occurring MH conditions.

To fill this gap, this project will conduct research in collaboration with a team of young adults with IDD and co-occurring MH conditions to develop and evaluate the feasibility of a peer mentoring intervention designed to meet the unique needs of this population. First, we will conduct interviews and focus groups with young adults ages 16–23 with IDD and co-occurring MH conditions to identify their desired outcomes for a peer mentoring intervention and the intervention delivery characteristics (e.g., duration, structure, format) that may support achievement of these outcomes. Then, we will consult with experts in peer-delivered mental health interventions to adapt existing peer mentoring interventions and develop a theory-driven peer mentoring intervention that meets the unique needs of young adults ages 16–23 with IDD and co-occurring MH conditions. Finally, we will evaluate the feasibility and social validity of the resultant intervention with a sample of 6 mentees. This research will result in the first peer mentoring intervention designed specifically to support the health and quality of life of young adults with IDD and co-occurring MH conditions.

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

- **Cheri Blauwet, M.D.**

Assistant Professor of Physical Medicine and Rehabilitation, Harvard Medical School;
Spaulding Rehab
Spaulding Rehabilitation Hospital

“Virtual Peer Health Coaching as an Effective Intervention for Increasing Physical Activity in Adolescents with Physical Disability”

Participation in physical activity (PA) confers clear physical and psychosocial benefits. Yet, many adolescents with physical disabilities such as cerebral palsy and spina bifida do not engage in regular PA, putting them at increased risk for the detrimental impact of sedentary lifestyles such as high rates of obesity/overweight – adverse health trends that continue into adulthood. To address this PA gap, we propose a feasibility pilot randomized controlled trial evaluating the utility of a peer health coach intervention to promote PA participation and to improve outcomes related to self–autonomy, self–efficacy, and quality of life in adolescents with physical disabilities. Peer health coaches will themselves be young adults with disabilities, trained in concepts of motivational interviewing and self–determination theory, enabling them to meet participants “where they are at” in their understanding of PA and readiness to change PA behaviors. This study will be novel given that: 1) for the first time, an adult peer health coaching model targeting PA will be adapted to the needs of adolescents with disabilities, 2) we will employ text messaging and other social media platforms that are highly relevant to an adolescent population, and 3) we will assess PA participation with use of ActiGraph activity trackers, designed to monitor both duration and intensity of PA in individuals with mobility impairment. The results of this study will be used to inform the design of a future, definitive RCT evaluating the efficacy of a peer health coaching intervention to create meaningful change in physical and psychosocial outcomes. By empowering adolescents with disabilities to take control of their own physical and psychosocial health, this work has the potential to impact the well–being and quality of life of participants for many years to come.

- **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 families of children with refractory chronic pain conditions awaiting admission to the PPRC at Boston Children’s Hospital at Waltham. Families approved for and awaiting PPRC admission will be randomized to receive PPRC-Prep along with usual care or to a comparison group receiving treatment as usual. Study aims include assessing the feasibility and acceptability of the intervention along with measuring its potential to increase readiness to engage in a self-management approach assessed at time of admission to the PPRC using established measures of readiness to change, pain acceptance, and committed action. We will also evaluate the effects of PPRC-Prep on program length of stay and on reductions of disability and pain at PPRC discharge and short-term (8-week) follow up through comparison of families who undergo PPRC-prep with families who do not undergo PPRC-prep. Demonstrating the feasibility and preliminary effectiveness of PPRC-Prep will enable us to establish this as a routine component of our approach to care for children with complex, refractory chronic pain and disability.

- **Ryan Martin, M.S., Ph.D.**

Research Scientist

May Institute Inc

“Feasibility of Home-Based Caregiver Training for Children with Autism Spectrum Disorder via Telehealth”

Many children with autism spectrum disorder (ASD) exhibit challenging behaviors that may interfere with their safety and affect their ability to access the community and form appropriate social relationships. Moreover, caregivers of children with ASD report challenging behaviors as a significant source of parenting strain and stress. A growing body of research has demonstrated the efficacy of behavioral parent training for reducing the disruptive behavior of children with ASD and reducing the stress of caregivers. Most research to date has focused primarily on implementing parent training in clinical settings, but caregivers often face numerous barriers to accessing these services. Thus, research examining the implementation of parent training in naturalistic environments is warranted. The present study will explore the feasibility of modifying the Research Unit on Behavioral Interventions (RUBI) Autism Network parent training program to be implemented via telehealth and accessed by caregivers in their homes. Feasibility will be evaluated by assessing the fidelity of implementation by caregivers and interventionists, in addition to caregivers' reported acceptability of the intervention. Further, to explore the impact of the intervention, we will compare pre- and post-intervention measures of children's challenging behavior and adaptive skills, as well as caregivers' reported self-efficacy and stress.

- **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

Tufts University

“Social Participation And Navigation (SPAN): Adaptation, Usability And Implementation For Youth and Transition-age Young Adult Brain Tumor Survivors”

Youth and transition-age young adult brain tumor survivors have challenges that hinder social participation in community, school and work life. Frequent hospitalizations, illnesses, treatment side-effects, and cognitive and behavioral sequelae can result in social isolation, depression, and limitations in important life roles, relationships and opportunities.

There is limited evidence specific to interventions that promote social participation of youth and transition age young adult brain tumor survivors. Thus, the overall purpose of this project is to adapt an existing app-based coaching intervention, Social Participation And Navigation (SPAN), initially designed for youth with traumatic brain injuries (TBI), to be relevant to the needs of youth and transition-age young adult brain tumors (ages 15–23). SPAN has four main components: 1) Virtual coaching (with college student coaches); 2) Initial coach training and weekly coach supervision; 3) SPAN website with brief tips and topics; 4) Goal planning web application. Promising results were found in a 10-week implementation trial of SPAN with 13 youth with brain injuries (TBI, n=9; brain tumor, n=4) related to goal attainment and on selected measures of social functioning and participation.

The specific aims of this demonstration project are to 1) Adapt the current version of SPAN based on existing and additional stakeholder feedback (n=6); 2) Assess initial feasibility and usability of the adapted SPAN with youth and transition-age young adult brain tumors in a four-week trial (n=5); and 3) Assess the preliminary effects of the adapted SPAN for promoting social participation in community, school and work settings in a larger scale 10-week implementation trial (n=10). The long-term objective is to determine whether the adapted SPAN has potential for widespread use specific to youth and transition-age young adult brain tumor survivors and others with social and executive functioning challenges and to seek additional funding to support this work and larger scale studies.

- **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 special education students ages 16–22 that also incorporates curricula on healthy relationships and sexuality education. The most current research shows that programs for women that include self–defense training, healthy relationships and sexuality education are the most effective at reducing rates of sexual assault. Yet, these effective programs have not been accessible to women with intellectual disabilities. They have also not been tested in mixed gender settings, which is important for disability populations as men with intellectual disabilities are also at high risk for victimization. For these reasons, expanding our evidence–based IMPACT: Ability safety education program to include healthy relationships and sexuality education – and developing corresponding research procedures that can be utilized to evaluate the program in this population – are critical next steps for reducing sexual assault victimization among teens with intellectual disabilities. This project will be implemented and facilitated by IMPACT, a program of Triangle, Inc. and Dr. Lindsay Orchowski of Brown University and Rhode Island Hospital; both leaders in the field of sexual assault prevention.

This research will be conducted in Boston Public Schools (BPS) with students who are educated in substantially separate special education classrooms due to functional limitations in self–care, receptive and expressive language, learning, self–direction, and capacity for independent living. These are students classified by the district as having been diagnosed with: Autism Spectrum Disorder, Emotional Impairment, Intellectual Impairment (mild, moderate, or severe), Developmental Delay, and specific learning disability. Triangle has a longstanding relationship with BPS. Over 500 students per year receive Triangle’s evidence–based IMPACT:Ability curriculum.

- **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 Pediatrics (DBP) and our affiliated Boston-area Community Health Centers (CHCs). Based on the national model created by the University of New Mexico, ECHO projects are designed to increase clinical workforce capacity and reduce disparities through the use of videoconferencing, mentoring in best practices, case-based learning, and on-going monitoring of outcomes. We will evaluate changes in provider skills and referral patterns as they relate to these aims, using historical group data and non-intervention patients as a comparison. At the end of the two-year project period and based on evaluation results and available resources, we will refine and extend this project to additional CHCs.

Deborah Munroe Noonan Memorial Research Fund 2021 Award Recipients

- **Kristin Long, Ph.D.**
Assistant Professor
Boston University

“Development Of A Family-Based Transition Planning Program For Culturally-Diverse Families Of Youth On The Autism Spectrum”

The transition to adulthood is a critical developmental period that sets up trajectories of adult functioning. For youth on the autism spectrum, this transition has been described as “falling off a cliff” due to the lack of available adult services and families feeling overwhelmed and unsupported. Although the transition to adulthood is universally challenging for families, it is also a time of increasing race/ethnicity-based service use disparities. Existing research suggests that autism-related transition planning and adult outcomes could be improved with attention to modifiable family-based treatment targets including parent self-efficacy, discussions about the future, and parent expectations for adult outcomes. However, no existing family-based programs focus on skills to navigate transition, are broad enough to include families of youth with a wide range of autism presentations, and consider cultural influences on transition processes or post-transition goals. Together, these gaps may limit existing programs’ usability in community settings that serve youth with a broad range of service needs. The proposed project takes a community-based approach to developing a transition planning program that accounts for flexibility across autism presentation and comorbidities, cultural values, family preferences, and readiness to engage in transition planning. Specific aims are to (1) develop the Families FORWARD (Focusing on Relationships, Well-being, and Responsibility ahead) program with culturally-diverse families and service providers and (2) conduct proof-of-concept testing with a stratified sample of families who identify as Black, Latinx, Asian, and non-Latinx white. The proposed program is novel in its proactive approach to considering diversity from the earliest stages of intervention development. The individualized nature of the program is expected to increase its ultimate acceptability and usability in community settings. This is the first step in a line of research to improve transition planning and decrease service use disparities across the transition to adulthood for youth on the autism spectrum.

- **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 increased PA and improvements to mood and executive functioning, such as self-regulation, with evidence that sleep and diet interventions also improve cognition and function in this population. The proposed study, GamerFit, pilots a 12-week randomized controlled intervention study with 46 youth with ASD, ages 10–14 years. GamerFit remotely delivers PA and telehealth coaching through a fully integrated, HIPAA-compliant mHealth application. The 12-week exergaming curriculum provided by the app delivers 3 exergaming sessions weekly, during which participants choose from a suite of developmentally appropriate exergames. The app interface provides youth with: 1) a weekly exergaming challenge menu, 2) PA and sleep tracking via an automated FitBit sync, 3) push notifications to access a coaching video library, 4) motivational text messaging, and 5) text reminders of upcoming intervention tasks. We propose to 1) examine the feasibility and acceptability of the 12-wk GamerFit intervention; 2) preliminarily test the hypothesis that GamerFit participation will increase total PA in the intervention group (n=23) compared to a waitlist control group (n=23) receiving a commercially available Fitbit application; and 3) explore changes in screen time, sleep hygiene, diet quality, mood, and perceived social support. If shown to be feasible, acceptable, and effective, GamerFit can provide a fully remote, inexpensive intervention to improve key health behaviors with low barriers to engagement. Improvement of these behaviors has been shown to bring about positive improvements in self-regulation, mood, and cognition. Additionally, telehealth coaching and family-based interventions can improve perceived social support. Long-term, these effects could extend beyond reducing chronic disease risk to better academic and social success.

- **Jaimie Timmons, M.S.W.**
Research Associate III and Program Manager
University of Massachusetts Boston

“Pathways to Daily Life and Employment in Healthcare for Youth with Down Syndrome”

The Institute for Community Inclusion (ICI) at the University of Massachusetts Boston, in collaboration with the Down Syndrome Program at Boston Children’s Hospital, and in consultation with the Institute for Human Development at the University of Missouri–Kansas City (UMKC–IHD), will develop, pilot, and evaluate a Pathways Demonstration for at least 40 parents of youth with Down syndrome ages 10–14. The ten-month intervention will support parents to prepare for a positive transition from high school to daily life and integrated employment. A transition planning portfolio based on content from UMKC’s Charting the LifeCourse will provide tools and resources, weekly electronic outreach via Facebook as a platform for family networking, connections to companion resources, and a standardized clinician protocol for engaging parents in a guided conversation about post-school life during patient encounters. Through provision of brief prompts or nudges (Dechausay & Anzelone, 2016), content will be chunked apart in micro-learning opportunities (Buchem & Hamelmann, 2010). Project goals include increasing the frequency with which hospital clinicians address transition preparation, strengthening the capacity of the Down Syndrome Program to deliver transition content, and improving parents’ visions for the future of their young adult. Pre- and post-test surveys administered to parents will measure their short-term and long-term expectations; their attitudes and beliefs about community and workplace inclusion; and their ability to identify and implement incremental actions that support the achievement of goals. Post intervention key informant interviews with parents, youth, and clinicians will focus on participants’ experiences, facilitators and barriers to engagement, and recommendations for refining the intervention in preparation for scaling up.

**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 co-created 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.