

# National Research Consortium on MHIDD

2021 Annual Report | February 2022

In 2019, the National Center for START Services at the University of New Hampshire Institute on Disability/UCED established the National Research Consortium (NRC) on Mental Health in Intellectual and Developmental Disabilities (MHIDD). The goals of the collaboration are to improve the mental health and well-being of individuals with IDD, their families, and communities; to foster collaboration among research institutions, practitioners, UCEDDs, providers, and people with lived experiences; to generate co-sponsorships and collaborative partnerships to fund innovative, startup projects; and to promote engagement with new researchers and trainees. The National Research Consortium on MHIDD is comprised of people with lived experiences (including self-advocates and family members), caregivers, trainees, researchers, policy experts, and clinicians from over 30 organizations across the United States, including several UCEDDs, medical schools, state health departments, and service providers (see Appendix for details on the list of all NRC participants).

Partnering with stakeholders in the prioritization, development, and dissemination of best-practice research will allow us to improve the quality of care delivered to those with IDD across the country. The Consortium aims to promote equity and inclusion by building a national community of practice and international partnerships. This work creates a vehicle for information dissemination, training resources, and peer-reviewed publications on factors that contribute to mental wellness for persons with IDD-MH. The National Center for START Services is uniquely positioned to advance this agenda by drawing on long-standing internal expertise as well as external research partnerships with universities and strategic partners across the country. Beyond scholars, the National Center for START Services is committed to partnering with self-advocates and families to help guide the research agenda and interpret the findings.

## Research Priorities

The research agenda for the Consortium was set by the NRC Board. We currently have five priority areas of research: 1) positive psychology and strengths-based practices; 2) evidence-based interventions to promote well-being; 3) participatory approaches to research; 4) cultural and linguistic competence; and 5) interdisciplinary and patient partnerships.

## Leadership, Board Members & Advisors



**Joan B. Beasley, PhD**  
Consortium Director  
Director  
National Center for  
START Services



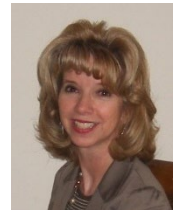
**Luther Kalb, PhD**  
Consortium Chair  
National Center for  
START Services  
Kennedy Krieger/Johns  
Hopkins



**Andrea Caoili, LCSW**  
Director of Consortium  
Operations  
National Center for  
START Services



**Melanie Hecker**  
Advocate  
Albany, New York



**Susan Klick**  
Family Member  
Hartford, Connecticut



**George Contos, JD**  
Chief Executive Officer



**Cheryl Karran, LMSW**  
Regional Director, CA  
Services



**Colleen Horton, MPA**  
Director of Policy



**Tawara Goode, MA**  
Director



**Roberto Blanco, MD**  
Clinical Associate  
Professor





**Matthew Wappett,  
PhD**  
Executive Director



**John Dickerson**  
Chief Executive Officer



**Pat Nobbie, PhD**  
*Disability Policy  
Engagement Director*



**Yona Lunsky, PhD**  
University of Toronto  
*Consortium Advisor*



**Angela Hassiotis,  
PhD**  
University College  
London  
*Consortium Advisor*

## Research Partners



## Calendar Year 2021 Budget

### Contributions

The National Research Consortium's full operating budget for 2021 was \$109,000. Monetary donations totaled \$50,000. In-kind contributions made up the remaining difference in the budget. These monies were spent across two domains: research and operations. A total of 90% of the 2021 budget was spent, leaving a balance of \$7,239 to be applied to the calendar year 2022 budget.

### Expenses: Research

A total of \$40,335 funded five NRC research projects awarded in 2020 and 2021. These funds came directly from monetary donations. Each project required a match for approval. A total of \$80,000 in matching funds were provided. As a result, \$120,335 was allocated for research in 2021. See 'Funded Projects' below for details.

### Expenses: Operations

Operating expenses for 2021 totaled \$27,426. This included National Center for START Services direct staff effort, digital/print material, and external consultative effort. These funds came directly from monetary donations.

## Funded Projects & Updates

### 2020 Grantees

#### Examining Cognitive Accessibility and Clinical Applications of the VIA Character Strengths Survey.

PI: *Ariel Schwartz, Assistant Professor, MGH Institute of Health Professionals*

**Aims:** 1) Examine the comprehensibility of the VIA Character Strengths Survey when used by adults with intellectual and/or developmental disabilities; and 2) Describe how knowledge of character strengths is used in clinical practice with adults with intellectual and/or developmental disabilities.

**Total Awarded: \$11,360.**

**Research institution's match: \$15,000.**

**Update:** Dr. Schwartz presented her initial findings from Aim 1 at the 2021 NRC Conference. She also had her Aim 1 manuscript accepted for publication in the *Journal of Positive Psychology*. The study found that clinicians utilize the VIA Survey to foster self-esteem and self-understanding, provide a framework for understanding strengths, communicate across service systems, and shape strengths-based interventions. Individuals with intellectual and/or developmental disabilities also endorsed use of the survey to increase their self-knowledge and self-esteem. For Aim 2, she has completed N=30 cognitive interviews and will conclude this project in 2022.

#### Citation

Schwartz, A., Caoili, A., Beasley, J., Kramer, J., & Kalb, L. (accepted) Clinical applications of the VIA Inventory of Strengths with Individuals with Intellectual/Developmental Disabilities. *Journal of Positive Psychology*.

#### Beat It: U.S.-Based Pilot Evaluation of the Behavioral Activation Intervention, Beat It, for Young Adults with ID.

PIs: *Dave Buck, PhD, Chattanooga Autism Center, TN; Roberto Blanco, MD, University of North Carolina, Chapel Hill, School of Medicine, NC*

**Aims:** 1) Ensure suitability of the Beat It intervention and accompanying manualized materials in the United States; 2) Ensure that the research group can administer Beat It with fidelity for up to 20 individuals with ID identified as having low mood or meet clinical criteria for depression; and 3) Evaluate the experiences and outcomes for patients and therapists.

**Total Awarded: \$17,000.**

**Research institution's match: \$30,000.**

**Update:** Beat It is an in-person intervention. As such, this project has seen significantly delays due to the COVID-19 pandemic. Beat It has recently received IRB approval from UNC and will begin recruiting

## 2020 Grantees (continued)

### Positive Mental Health and Autism Spectrum Disorders.

*PI: Luke Kalb, PhD, Kennedy Krieger Institute, Johns Hopkins University, MD*

**Aims:** Examine the: 1) profiles of well-being among parents raising a child with autism spectrum disorders (ASD); 2) psychometric characteristics of the PERMA Profiler, a measure of well-being, among adults with ASD; 3) profiles of well-being among adults with ASD; and 4) correlates of well-being among adults with ASD and caregivers of children with ASD.

**Total Awarded: \$7,000.**  
**Research institution's match: \$15,000.**

**Update:** This study has completed data collection from SPARK, a national ASD registry. In total, over N=1000 respondents replied to the survey (~N=500 caregivers raising a child with ASD and ~N=500 adults with ASD). The team presented their Aim 1 findings at the 2021 NRC meeting, has submitted them for presentation at the 2022 INSAR conference ([www.autism-insar.org](http://www.autism-insar.org)), and is drafting a manuscript. The funds for this study have allowed for recruitment of a Johns Hopkins PhD student, Luke Grosvenor, to lead the project. Thus far, this study has found that the PERMA Profiler works well (psychometrically) in adults with ASD. This can lead to increased used of this self-report measure in ASD studies.

#### Citation

Grosvenor, L., Hood-Bey, C., Beasley, J., Hologue, C., Errichetti, C., McLaren, J., & Kalb, L. (2022) Psychometric properties of the PERMA Profiler in autistic adults. INSAR; Austin, TX.

### Examining the Mental Health of Autistic College Adults.

*PI: Brian Freedman, PhD, Senior Associate Director, University of Delaware Center for Disability Studies, DE*

**Aims:** 1) Examine the internal construct validity and reliability of a commonly used mental health instrument in college counseling centers, the Counseling Center Assessment of Psychological Symptoms-62 item (CCAPS-62), for students on the autism spectrum; 2) Understand the specific mental health needs of college students on the autism spectrum when compared to college students with other disabilities and no disabilities; and 3) Explore predictors of mental health needs of autistic college students.

**Total Awarded: \$9,360.**  
**Research institution's match: \$15,000.**

**Long-term Goal:** Dr. Freedman and his team have conducted the analysis for all aims. They presented their findings at the 2021 NRC meeting. The results suggest the CCAPS is valid for use among college students with ASD. They identified the top mental health needs (e.g., social anxiety, frustration) among this population as well as predictors of mental health issues (e.g., prior trauma, sexual orientation). The team submitted two presentation abstracts in 2022.

#### Citation

Monahan, J., Freedman, B., Singh, V., & Kalb, L. (2022) Validating the Counseling Center Assessment of Psychological Symptoms for Autistic Adults: A Step Towards Better Understanding of Mental Health. INSAR; Austin, TX.

Edmonson, C., Monahan, J., Freedman, B., Singh, V., & Kalb, L. (2022) Psychological Symptoms of College Autistic. Postsecondary Training Institute. University of Connecticut.

## 2021 Grantees

### Psychological Flexibility in Adults with ASD: Psychological Distress in the Context of COVID-19.

*PI: Ty Aller, PhD, LMFT, Researcher & Licensed Marriage and Family Therapist, University of Utah, UT*

**Aims:** 1) Explore how psychological flexibility influences psychological distress in adults with ASD in the context of COVID-19 with a pilot epidemiological study; 2) Establish the dimensionality, internal consistency, test-retest reliability, and the concurrent and convergent validity of the Acceptance and Action Questionnaire II (AAQ-II) in adults with ASD; and 3) Establish the dimensionality, internal consistency, test-retest reliability, and the concurrent and convergent validity of the Brief Experiential Avoidance Questionnaire (BEAQ) in adults with ASD.

**Total Awarded: \$10,000.**

**Research institution's match: \$10,000.**

**Updates:** Dr. Aller and his team have completed data collection through SPARK. A total of N=453 participants engaged in his survey (caregivers of children with ASD). He is conducting the analysis and provided an update on the study methodology at the 2021 NRC conference. Dr. Aller has registered his study at OSF (<https://osf.io/8g4ha>) and is crafting a manuscript for the *Journal of Contextual Behavior*. He also leveraged these data for another grant submission to develop an online intervention for autistic adults.

### Using Mixed-Reality Simulation to Train School-based Mental Health Professionals How to Support Students with Developmental Disabilities with Co-occurring Mental Health Concerns.

*PI: Emily Graybill, PhD, Director, Center for Leadership in Disability, Georgia State University, GA*

**Aims:** Using Mixed-Reality Simulation, the aims of this project are to increase: 1) awareness of mental health concerns in students with developmental disabilities; 2) knowledge of signs and symptoms of mental health concerns of students with disabilities; and 3) skills in supporting students with developmental disabilities who are showing signs of mental health concerns.

**Total Awarded: \$15,000.**

**Research institution's match: \$15,000.**

**Update:** This project was funded in the fall of 2021. It is just getting underway.

## 2021 Events

### MARCH

NRC Board Meeting

### JULY

2021 NRC Innovation Award Applications Due

### AUGUST

NRC Board Meeting and Funding Decisions  
2021 Innovation Award Announced

#### Donors & Partners



**Positive Mental Health and Autism Spectrum Disorders**  
*PI: Luke Kautz, PhD, Kennedy Krieger Institute, Johns Hopkins University, MD*  
**Abstract:** Examine the 1) profiles of well-being among parents raising a child with Autism Spectrum Disorders (ASD); 2) psychometric characteristics of the PERMA-Profiles, a measure of well-being among adults with ASD; 3) profiles of well-being among adults with ASD; and 4) correlates of well-being among adults with ASD and caregivers of children with ASD.  
**Long-term Goals:** To advance research and measurement of well-being on among those with ASD and their families. This is a major gap in the literature. Previous research is highly focused on deficits.  
**Total Awarded:** \$7,000, *Research Institution's match:* \$15,000

**Using Mixed-Reality Simulation to Train School-based Mental Health Professionals how to Support Students with Developmental Disabilities with Co-occurring Mental Health Concerns**  
*PI: Emily Graybill, PhD, Director, Center for Leadership in Disability, Georgia State University*  
**Goals:** Through this project, we will train 20 school psychology students and 20 school counseling students on how to build the competence to support the mental health concerns of students with developmental disabilities (MH/DD) in schools. We will measure their attitudes, knowledge, and skills related to receiving training on supporting students with MH/DD.  
**Abstract:** 1) Increase awareness of mental health concerns in students with developmental disabilities; 2) Increase knowledge of signs and symptoms of mental health concerns of students with disabilities; and 3) Increase skills in supporting students with developmental disabilities who are showing signs of mental health concerns.  
**Total Awarded:** \$15,000

**Psychological flexibility in adults with ASD: Psychological distress in the context of COVID-19**  
*PI: Ty B. Acker, PhD, LMFT, Utah State University Center for Persons with Disabilities UCEDD*  
**Abstract:** 1) Explore how psychological flexibility influences psychological distress in adults with ASD in the context of COVID-19 with a pilot epidemiological study; 2) Establish the dimensionality, internal consistency, test-retest reliability, and the concurrent and convergent validity of the Acceptance and Action Questionnaire II (AAQ-II) in adults with ASD; 3) Establish the dimensionality, internal consistency, test-retest reliability, and the concurrent and convergent validity of the Brief Experiential Avoidance Questionnaire (BEAQ) in adults with ASD; 4) Provide research opportunities for undergraduate and/or graduate research assistants and UCEDD trainees to learn more about the intersection of mental health and intellectual/developmental disabilities.  
**Total Awarded:** \$15,000

**Beat It: US Based Pilot Evaluation of the Behavioral Activation Intervention, Beat It, for Young Adults with ID**  
*PI: Dave Bark, PhD, Chattanooga Autism Center, TN; Roberto Blanco, MD, UNC School of Medicine, NC*  
**Abstract:** 1) Ensure suitability of the Beat It intervention and accompanying manualized materials in the US; 2) Ensure that the research group can administer Beat It with fidelity for up to 20 individuals with IDD identified as having low mood or meet clinical criteria for depression; and 3) Evaluate the experiences and outcomes for patients and therapists.  
**Long-term Goals:** To bring an evidence-based depression intervention, from the UK, to the US. This pilot work will lay the ground needed for a large, randomized trial in the future.

### APRIL

Bi-Annual, Full NRC Meeting

### AUGUST

NRC Board Meeting and Funding Decisions  
NRC Partnerships Lead to [\\$5 Million PCORI Grant](#)



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News - CSS Approved for \$4.86 Million in Research Funding for Study of Telemental Health Services on Mental Health Outcomes for People with IDD

## CSS Approved for \$4.86 Million in Research Funding for Study of Telemental Health Services on Mental Health Outcomes for People with IDD

Date: 08/16/2021

DURHAM, NH – Dr. Joan B. Beasley and a research team from the Center for START Services at the Institute on Disability (IOD) at UNH has been approved for a \$4.86 million funding award by the Patient-Centered Outcomes Research Institute (PCORI) for their study: Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities. The project will include partners from the University of Florida and Johns Hopkins Kennedy Krieger Institute.

Individuals with IDD are twice as likely to have mental health needs compared to the national average and are far less likely to have access to quality preventive mental health treatments. As a result, many patients and families turn to costly, ineffective, and often traumatic emergency services resulting in poor outcomes. Recently, telehealth services, which are provided through the internet and/or phone, have become a more common yet unproven strategy for delivering mental health care to individuals with IDD. The project will compare an in-person to a telehealth-delivered crisis prevention program for youth and young adults with IDD. Both interventions will be delivered within START (Systemic, Therapeutic, Assessment, Resources, and Treatment), a national model of crisis prevention and intervention services for people with IDD. The project will engage patient partners and stakeholders throughout the design, methods, and implementation.

"This study was selected for PCORI funding not only for its scientific merit and commitment to engaging patients and stakeholders in research, but also for its potential to fill an important evidence gap and give people information to help them better assess their care options," said PCORI Executive Director Na'kela L. Cook, MD, MPH. "We look forward to following the study's progress and working with the Institute on Disability to share the results."

IOD's study was selected for PCORI funding through a highly competitive review process in which patients, clinicians, and other stakeholders joined clinical scientists to evaluate the proposals. Applications were assessed for scientific merit, how well they will engage patients and other stakeholders, and their methodological rigor among other criteria.

### OCTOBER

NRC Annual Conference and Meeting

## Self-Advocate Highlights by Melanie Hecker, MPA

When I was growing up as a child who was both autistic and had mental health conditions, everything about my life was often decided for me. Everything from what classes I took in school to which types of extracurriculars I could take part in was predetermined by the neurotypical adults in my life. It very often seemed like my voice did not matter. In the past, research surrounding people with intellectual and developmental disabilities was very much the same way. Research usually did not incorporate the voices of people with IDD-MH or even take their concerns into consideration.

Upon being asked to join the START National Research Consortium, I realized I was going to be a part of something that would change the status quo. Any research organization which would want a developmentally disabled person on their leadership team is one dedicated to ensuring the voices of people with disabilities are centered in its work. As time went on, the START National Research Consortium fully lived up to that ideal. I am considered an equal member of the team, with my voice mattering just as much as anyone else's. The rest of the team elevates my voice in decision making not just because I am a trained analyst, but also because I am a person with lived experiences. The lived experiences of other self-advocates in the START network are also frequently utilized, ensuring that our work contains more than just token representation.

I have been able to do amazing work through the START National Research Consortium. Every one of our projects is centered around directly improving the lives of people with developmental disabilities, intellectual disabilities, and mental health conditions. The direct involvement of self-advocates such as myself ensures that all of our work is able to meet its goals of truly making a difference in our lives. I cannot wait to see what the future of the START National Research Consortium has in store.

## NRC Annual Meeting, October 2021

The Annual Meeting was attended by over 50 research partners across the United States and began with an overview of the Consortium's background, purpose, and priorities. The keynote presentation was the **Transforming Research Workshop**. This presentation and subsequent breakout discussion focused on how to meaningfully include people with lived experiences in research. Using the lessons from this presentation, Consortium members discussed practical methods for the inclusion of people with lived experiences and developed goals for the Consortium to put these methods into action.

After this keynote presentation, updates were given on the six research projects currently being funded by the Consortium. All projects were determined to be running smoothly. To finish the day, the Consortium prepared for our next steps to support our research projects.

## Next Annual Meeting

The next annual meeting will be held in person in October 2022 in Baltimore, Maryland. The keynote presentation will be determined at a later time.

## Appendix

### NRC Leadership Team

- Joan B. Beasley, PhD, *Principal Investigator* – Research Associate Professor at the University of New Hampshire, Institute on Disability/UCED and Director of the National Center for START Services
- Luke Kalb, PhD, *Consortium Chair* – Assistant Professor, Kennedy Krieger Institute and Johns Hopkins University
- Andrea Caoili, LCSW, *Director of Consortium Operations* – Director of Research and Quality Assurance at the National Center for START Services, University of New Hampshire, Institute on Disability/UCED

### Board Members

- Roberto Blanco, MD, Assistant Professor, Division of Child and Adolescent Psychiatry; Co-Director, Program on Neurodevelopmental Psychiatry, University of North Carolina School of Medicine – Chapel Hill, NC
- George Contos, JD, Chief Executive Officer, YAI – New York, NY and San Jose, CA
- Ravi Dahiya, MPA, Chief Program Officer, YAI – New York, NY and San Jose, CA
- John Dickerson, CEO, Quillo – Indianapolis, IN
- Tawara Goode, MA, Director, Georgetown University Center for Child and Human Development/UCEDD; PI, Leadership Institute for Cultural and Linguistic Competence; Assistant Professor, Department of Pediatrics, Georgetown University Medical Center - Washington, DC
- Melanie Hecker, Self-Advocate – Albany, NY
- Colleen Horton, MPA, Director of Policy, Hogg Foundation at the University of Texas at Austin – Austin, TX
- Susan Klick, Family Member – Hartford, CT
- Patricia Nobbie, PhD, Director of Disability Policy Engagement, Anthem – Washington, DC
- Matthew Wappet, PhD, Executive Director & Research Associate Professor, Utah State University Center for Persons with Disabilities/UCEDD – Logan, UT

### Advisors

- Angela Hassiotis, MRCPsych, MA, PhD, Professor of Psychiatry of Intellectual Disability, University College London
- Yona Lunsy, PhD, Director, Azrieli Adult Neurodevelopmental Centre; Senior Scientist, Adult Neurodevelopment and Geriatric Psychiatry Division; Director, Health Care Access Research and Developmental Disabilities (H-CARDD) Program; Professor in the Department of Psychiatry, University of Toronto; Adjunct Scientist, ICES

### Research Partners

- Chithra Adams, PhD, Director of Evaluation, University of Kentucky Human Development Institute/UCED – Lexington, KY
- Dan Baker, PhD, Internal Reviewer, Positive Support Lead, Minnesota Department of Human Services – St. Paul, MN
- Jarrett Barnhill, MD, Professor and Director, UNC Developmental Neuropharmacology Clinic, University of North Carolina Chapel Hill Medical School – Chapel Hill, NC
- Jim Bedford, MD, Assistant Professor, University of North Carolina Chapel Hill Medical School – Chapel Hill, NC
- Roberto Blanco, MD, Assistant Professor, University of North Carolina Chapel Hill Medical School – Chapel Hill, NC
- Alixe Bonardi, MPA, MS, Director of IDD Services Research, Human Services Research Institute – Cambridge, MA
- Meg DePasquale, DSW, Director of Clinical Services, Maryland Department of Health – Baltimore, MD
- Brian Freedman, PhD, Associate Director, University of Delaware Center for Disability Studies/UCEDD – Newark, DE
- Calliope Hologue, PhD, Postdoctoral Fellow, Johns Hopkins University/Kennedy Krieger Institute
- Lisa Hovermale, MD, Psychiatrist, Maryland Department of Health – Baltimore, MD
- Diane Jacobstein, PhD, Associate Professor, Georgetown University Center for Child and Human Development – Washington, DC
- Kathleen Shepperd Jones, PhD, Director, University of Kentucky Human Development Institute/UCED – Lexington, KY
- Jessica Kramer, PhD, OTR/L, Associate Professor, University of Florida – Gainesville, FL
- Jennifer McLaren, MD, Psychiatrist, Dartmouth Hitchcock Clinic – Hanover, NH
- Marian E. Ofonedu, PhD, LCSW, Director of Training, Maryland Center for Developmental Disabilities/UCEDD – Baltimore, MD
- Jenny Sladen, Director of National Initiatives, The Arc – Washington, DC
- Ariel Schwartz, PhD, Postdoctoral Fellow, Boston University – Boston, MA
- Marc Tasse, PhD, Director, The Ohio State University Nisonger Center/UCEDD – Columbus, OH
- Dan Tomasulo, PhD, MFA, MAPP, incoming Academic Director, Spirituality Mind Body Institute (SMB) MA Degree Program; Core faculty, Lecturer, Department of Clinical Psychology, Teachers College, Columbia University – New York, NY