

National Research Consortium on MHIDD

2022 Annual Report | February 2023

In 2019, the National Center for START Services at the University of New Hampshire Institute on Disability established the National Research Consortium (NRC) on Mental Health in Intellectual and Developmental Disabilities (MHIDD). The goals of the consortium 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
Institute on Disability
University of New
Hampshire



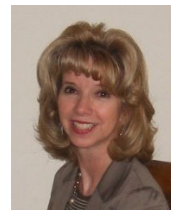
Luther Kalb, PhD
Consortium Chair
National Center for
START Services
Kennedy Krieger
Johns Hopkins



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



Micah Peace Urquilla
Research and Training
Assistant
National Center for
START Services



Susan Klick
Family Member
Hartford, Connecticut



Ravi Dahiya
Chief Program Officer

Seeing beyond disability.



Cheryl Karran, LMSW
Regional Director
CA Services

Seeing beyond disability.



Angela Ott
Policy Fellow



Tawara Goode, MA
Director

Center for Child and
Human Development



Roberto Blanco, MD
Clinical Associate
Professor
 | 
SCHOOL OF MEDICINE



**Matthew Wappett,
PhD**
Executive Director



John Dickerson
Chief Executive Officer



Pat Nobbie, PhD
*Disability Policy
Engagement
Director*



**Kelly Nye-Lengerman,
PhD, MSW**, Director,
Institute on Disability,
University of New
Hampshire



**Patricia Wright,
PhD, MPH**
Executive Director



Yona Lunsky, PhD
University of Toronto
Consortium Advisor



Angela Hassiotis, PhD
University College
London
Consortium Advisor

Research Partners



Calendar Year 2022 Budget

Contributions

As of January 2023, the NRC has a cash fund balance of \$162,917 available for innovation awards and other expenses. A total of \$75,000 in-kind resources were provided including board participation, donated space from Kennedy Krieger Institute, and leadership and operations support from NCSS.

Expenses: Research

A total of \$120,335 was available for research in 2021, which continued into calendar year 2022. Innovations grant submissions are on accepted on a rolling basis. See 'Funded Projects' below for details.

Expenses: Operations

Operating expenses for 2022 totaled \$55,367. Operating expenses included planning and delivery of the annual meeting, travel and participation costs for self-advocates and family members, NCSS in-kind direct staff effort, digital/print material, and external consultative effort.

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), 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 use of this self-report measure in ASD studies.

Citation

Grosvenor, L., Hood-Bey, C., Beasley, J., Holingue, 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.

2022 Events

MARCH

NRC Board Meeting

SEPTEMBER

2022 NRC Innovation Award Applications Due
(extended to rolling basis)

APRIL

Bi-Annual, Full NRC Meeting

OCTOBER

NRC Annual Conference and Meeting

Dr. Joan Beasley, Research Professor, Director, National Research Consortium on MH-IDD, presented the founding members of the Consortium board with clocks to commemorate the inaugural three years.



Dr. Andrew Jahoda, Professor of Learning Disabilities, University of Glasgow, gave the keynote presentation entitled "Improving Access to Psychological Therapies for People with Intellectual Disabilities and Mental Health Problems: Talking the Talk and Walking the Walk."



An expert panel was led by moderator Andrea Caoili, LCSW, Director of Operations, National Research Consortium. In addition to Dr. Beasley and Dr. Jahoda, other panelists included Dr. Luke Kalb, Chair START Research Committee and Assistant Professor at Kennedy Krieger, Dr. Yona Lunsky, and Mx. Micah Peace.



NRC Annual Meeting, October 2022

The National Research Consortium on Mental Health in Intellectual and Developmental Disabilities celebrated the completion of the inaugural three years at their annual meeting on Monday, October 17 in Baltimore, MD. Approximately 45 people attended in person at Kennedy Krieger Institute or via Zoom. Sponsored through a collaborative national partnership with oversight by the National Center for START Services, University of New Hampshire Institute on Disability, the consortium seeks to promote strength based research to improve the mental health and wellbeing of individuals with IDD, their families and communities.

Dr. Joan Beasley, Research Professor, Director, National Research Consortium on MH-IDD, presented the founding members of the Consortium board with clocks to commemorate the occasion. "I am most proud of the research and publications that resulted from our first three years and of the partnerships that continue to grow," Dr. Beasley said.

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Dr. Andrew Jahoda, Professor of Learning Disabilities, University of Glasgow, gave the keynote presentation entitled "Improving Access to Psychological Therapies for People with Intellectual Disabilities and Mental Health Problems: Talking the Talk and Walking the Walk."

A discussion on lived experience was led by Tawara Goode, Director, National Center for Cultural Competence, Georgetown University Center for Excellence in Developmental Disabilities. An expert panel was led by moderator Andrea Caoili, LCSW, Director of Operations, National Research Consortium. In addition to Dr. Beasley and Dr. Jahoda, other panelists included Dr. Luke Kalb, Chair START Research Committee and Assistant Professor at Kennedy Krieger, Dr. Yona Lunsky, and Mx. Micah Peace.

Next Annual Meeting

The next annual meeting will be held in person in October 2023 in Baltimore, MD. 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 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

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
- 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
- Micah Peace, Self-Advocate – Louisville, KY
- Angela Ott, 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
- Kelly Nye-Lengerman, PhD, Director, Institute on Disability University of New Hampshire -Durham, NH
- Patricia Wright, PhD, MPH, Executive Director, Proof Positive: Autism Wellbeing Alliance - New York, NY

Advisors

- Angela Hassiotis, MRCPsych, MA, PhD, Professor of Psychiatry of Intellectual Disability, University College London
- Yona Lunskey, 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 Holingue, 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