



University of
New Hampshire
Institute on Disability

National Research Consortium on MH-IDD

FISCAL YEAR 2025 REPORT | JULY 2025

Founded in 2019, the National Research Consortium on MH-IDD (NRC) is hosted by the University of New Hampshire's Institute on Disability UCEDD and funded through the contributions of organizations with representatives in our governing board. The wider consortium is comprised of people with lived experience of IDD-MH, family members, caregivers, trainees, researchers, policy leaders, and clinicians from over 30 organizations across the United States, including several University Centers of Excellence in Developmental Disabilities (UCEDDS), medical schools, state health departments, and service providers.

The goals of the collaboration are to:

1. Improve the mental health and well-being of people with IDD along with their families and communities
2. Foster collaboration among research institutions, practitioners, UCEDDS, providers, and people with lived experiences
3. Generate co-sponsorships and collaborative partnerships to fund innovative, startup projects
4. Promote engagement with new researchers and trainees

The Consortium aims to promote equity and inclusion by building a national network in the development and implementation of research with local, national, and international partners. The NRC serves as a platform for disseminating information, providing training, allocating resources, and sharing ideas, including peer-reviewed publications, on factors that contribute to mental wellness for people with IDD-MH.

DIRECTOR'S REPORT

We want to first take the time to thank Dr. Luke Kalb from Kennedy Krieger Institute for his time as the NRC Chair. While Dr. Kalb stepped back from this role he will remain an active member of the governing board and Kennedy Krieger will continue to host our annual meetings. Speaking of Lukes, we are happy to announce that Dr. Luke Reynard, the Executive Director at NFI North, a provider partner, will be our new Chair. Dr. Reynard has been a member of the NRC team from its launch, and we are delighted that he has taken on this role.

Needless to say this has been a challenging year, and we are grateful for the joint partnership and continued commitment of NRC leadership in pursuit of a shared vision toward supporting the development of inclusive, strength-based and meaningful mental health research to improve the health and well-being of people intellectual and developmental disabilities. Despite challenges faced in the research arena, great work continues to flow through the NRC. This year it seems even more important to learn from and share ideas with our awardees and members at our upcoming annual meeting, webinars, and publications.

In addition to our partnership with the Developmental Disabilities Network Journal (DDNJ), in 2024 we launched a webinar series, hosted by Georgetown University's National Center for Cultural Competence and UCEDD. The goal of these webinars is to expand the capacity of the NRC to disseminate information and research to a wider audience. The first two webinars have been well-received, and we look forward to two more planned for the coming year.

Our most recent development is the YAI MH-IDD Research Poster Presentation as part of our 2025 Annual Meeting. Posters were submitted by new researchers interested in sharing their ideas, and one will be selected by the NRC board to be presented by the author at the NRC Annual Meeting in October. Runners up will be featured on the NRC's website.

We look forward to our upcoming meeting, research, publications, and webinars in the coming year. Thank you to our leadership, board members, and advisors who contribute time and resources.

LEADERSHIP, BOARD MEMBERS & ADVISORS



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Consortium Director
Institute on Disability,
University of New Hampshire



Luke Reynard, Ph.D.

Executive Director
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Andrea Caoili, MSW, LCSW, Ed.D.

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Micah Peace Urquilla

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RESEARCH PARTNERS



Human Services
Research Institute



Hogg Foundation
for Mental Health



**THE OHIO STATE
UNIVERSITY**
NISONGER CENTER

FY 2025 BUDGET

Contributions

Contributions from July 1, 2024 through June 30, 2025 are included in this report. Total contributions were \$213,231, consisting of \$108,334 in cash donations and \$104,897 of in-kind contributions. In-kind contributions included board member participation, oversight and operational personnel effort, annual meeting space and support. Some NRC oversight and operational support is donated by the University of New Hampshire Institute on Disability.

Expenses: Operations

Operating expenses totaled \$112,878. Operating expenses included operations staff effort, planning and delivery of the annual meeting, travel and participation costs for invited speakers, self-advocates, and family members, digital/print material, and external consultative effort.

Expenses: Innovations in Research Awards

During the reporting period a total of \$70,000 was awarded for innovations in research, consisting of one, 2-year award for the project “Development and Evaluation of the We All Matter Peer Virtual Support Group: Implementation and Resource Guides, & Evaluation Tools”.

2025 RESEARCH PRIORITIES

The research agenda for the Consortium was set by the NRC Board. The current priority areas of research are:

1 .	Application of positive psychological methods
2 .	Development of evidenced-based inclusive interventions
3 .	Building capacity to reduce service disparities
4 .	Implementation of accessible measures

The NRC emphasizes and prioritizes inclusive and strength-based research methodologies.

Newly Funded Research Projects

In 2025 the NRC conducted a successful call for proposals that resulted in the funding of one full term research project. This project is conducted by a researcher from Kansas University Medical Center, Dr. Jessica Schuttler.

Development and Evaluation of the We All Matter Peer Virtual Support Group: Implementation and Resource Guides, & Evaluation Tools

Jessica Schuttler, Ph.D., Licensed Psychologist, Associate Professor, Kansas LEND (KU Medical Center), Kansas Council on Developmental Disabilities, Kansas University Center on Disabilities

We All Matter is a virtual peer-peer support group founded by Whit Downing, a Kansas mental health and disability advocate. This project aims to develop an implementation guide and resource guide for We All Matter in partnership with group members, as well as to evaluate group participation impact on members' mental well-being as well as their sense of belonging, defined as emotional support. We will gather both quantitative and qualitative information about program impact, and about ongoing mental health support needs for people with IDD in the state of Kansas.

Currently Funded Research Projects

Promoting Postpartum Mental Health for Women with IDD: A Strengths-Based Contextual Study

Drs. Miriam Heyman and Anne Valentine, Brandeis University, Lurie Institute for Disability Policy, Heller School for Social Policy and Management

Project Aims

The proposed qualitative study will explore experiences related to postpartum mental health for women with IDD, including opportunities to leverage contextual and internal resources to support wellbeing, with a focus on women from racial and ethnic minority communities. Specific aims are outlined below.

Aim 1:

Examine experiences, including perceived needs and / or opportunities for additional support, related to postpartum mental health for women with IDD, including women from racial and ethnic minority communities.

Aim 2:

Examine contextual and internal resources that promote postpartum mental health for women with IDD, including women from racial and ethnic minority communities.

Promoting Self-Determination in Psychotherapy

Richard Champman, PhD, The Partnership for People with Disabilities, School of Education, Virginia Commonwealth University

This project will develop an intervention manual that is based on the Self Determined Learning Model of Instruction and pilot a 10-week intervention with a group of people with IDD-MH.

Determining the Feasibility, Acceptability, and Preliminary Efficacy of an Online, Self-guided, Single-Session ACT Program to Improve Quality of Life for Autistic Adults Experiencing Mental Health Concerns

Principal Investigator: Ty Aller, PhD, of the Institute for Disability, Research, Policy, and Practice (IDRPP), Utah State University

This study will address issues related to acceptability and accessibility of mental health treatment for autistic adults by co-creating an online, single-session, Acceptance and Commitment Therapy (ACT)-based intervention with a participatory research team. Once created, the team will then determine its feasibility, acceptability, and preliminary efficacy in an open trial of the newly developed single-session intervention.

Survey of Psychological Training in Autism and Intellectual Disability

Amy Keefer, PhD, the Center for Autism and Related Disorders at Kennedy Krieger Institute, Johns Hopkins

This project aims to examine current training opportunities in autism and intellectual disability research as well as the perceptions of, comfort with, interest in and knowledge about psychological services for autistic and intellectually disabled individuals. This information will be used to identify useful training resources and potential barriers to improving training within graduate psychology programs.

WEBINAR SERIES

In partnership with Georgetown University the NRC held two webinars in 2025. The first webinar, Truth and Reconciliation: Building research capacity of young adults with intellectual and developmental disabilities and mental health service experiences, families, and clinicians, was presented by Dr. Jessica Kramer, University of Florida, Demetra Grigley, National Center for START Services, and Vee Maybin, Advocate.

The second, Research Implications of Character Strengths and Abilities Within Disabilities, was presented by Dr. Dan Tomasulo of Columbia University.

The webinars were attended by policy makers, researchers, graduate students and advocates from across the country. Their recordings have been posted on the NRC's website as a resource.

NRC ANNUAL MEETING

October 2024

The National Research Consortium on Mental Health in Intellectual and Developmental Disabilities (MH-IDD) held their sixth annual meeting on October 16 at Kennedy Krieger Institute in Baltimore, MD, which featured guest speakers from partner institutions across the country.

More than 35 researchers, policy makers, family members, self-advocates, and providers joined in to discuss the theme of this year's conference, "Inclusive Practices and Positive Approaches in IDD Research."

Presentations included:

Inclusive Research: Implications for the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities

Professor Tawara Goode, Director, National Center for Cultural Competence, Georgetown University

Including Self-Reported Behavioral Health Symptoms from Adults with ID in Estimating the Point Prevalence of Comorbidity

Susan Haverkamp, PhD, Director of Health Promotion and Healthcare Parity, The Nisonger Center, The Ohio State University

Marc J. Tassé, PhD, Director, The Nisonger Center, The Ohio State University

Importance of Research Participation to Self-Advocacy

Melanie Hecker, MPA

Jessica Kramer, PhD, OTR/L, FAAIDD, Associate Professor, Department of Occupational Therapy, University of Florida

Beat It: A Behavioural Activation intervention for People with intellectual Disabilities and Low Mood

Andrea Caoili, EdD, Director of Research and Quality Assurance, National Center for START Services®, University of New Hampshire

Karen Weigle, PhD, Associate Director/Director of Program Development, National Center for START Services®, University of New Hampshire

Additionally, each funded research project was presented to attendees by members of their team.

All presentations were recorded and posted on the NRC's website.

2025's Annual Meeting

The next annual meeting will be held on October 7th, 2025, at Kennedy Krieger Institute in Baltimore, MD. It will feature presentations by researchers from the University of Florida and the Ohio State University as well as a presentation by the winner of the YAI MH-IDD Research Poster Presentation.



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