

JULY 2024

# Annual Report

National Research Consortium on MH-IDD



This report covers the 18-month period from January 2023 to June of 2024. The change of dates better aligns with the funding cycle. Future reports will remain annual from July 1st to June 30th of the following year.

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Founded in 2019, the National Research Consortium on MH-IDD (NRC) is operated 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 self-advocates and 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 NRC goals are to:**

- Improve the mental health and well-being of individuals with IDD, their families, and communities by advancing research on strengths-based, inclusive, and evidence-based practices.
- Foster collaboration among research institutions, practitioners, UCEDDS, providers, family members, and self-advocates.
- Generate co-sponsorships and collaborative partnerships to fund innovations in research; and 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 creates a vehicle for information dissemination, training, resource allocation, and dissemination of ideas including peer-reviewed publications on contributors to mental wellness for persons with IDD-MH.

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# Director's Report

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This was an active time with four new NRC innovation grant awards, in which we increased both the maximum amount awarded per grant to \$35,000 per year and the time allotted for completion to a maximum of two years. This increased the number of submissions we received and reviewed. We are looking forward to hearing from our awardees at our upcoming annual meeting held at Kennedy Krieger Institute, in October 2024.

This year the NRC also partnered with the Developmental Disabilities Network Journal (DDNJ). Luke Kalb and I served as guest Editors of a special issue titled Mental Health Aspects of Intellectual and Developmental Disabilities. We are grateful to the wonderful collaboration and leadership of Dr. Matt Wappett, and Utah State University.



Beginning in 2025 the Georgetown University UCEDD will host two NRC webinars annually. The goal of these webinars is to expand the capacity of the NRC to disseminate information and research to a wider audience.

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.

A handwritten signature in cursive script that reads "Joan B. Beasley".

**Joan B. Beasley, Ph.D.**

Consortium Director  
Institute on Disability, University of New Hampshire

# Leadership, Board Members & Advisors



**Joan B. Beasley, Ph.D.**  
Research Professor  
Institute on Disability,  
University of New Hampshire



**Luther Kalb, Ph.D.**  
Consortium Chair  
National Center for START Services,  
Kennedy Krieger, John Hopkins



**Andrea Caoili, MSW,  
LCSW, Ed.D.**  
Director of Consortium Operations  
National Center for START Services



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



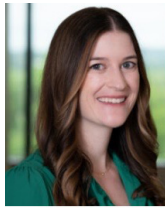
**Susan Klick**  
Family Member  
Hartford, Connecticut



**Ravi Dahiya**  
Chief Program Officer  
YAI



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



**Alison Mohr Boleware, LMSW**  
Director of Policy  
Hogg Foundation for Mental Health



**Tawara Goode, MA**  
Director  
Center for Child and  
Human Development,  
Georgetown University



**Patricia Dautel Nobbie, Ph.D.**  
 Disability Policy Engagement  
 Director  
 Elevance Health



**Matthew Wappett, Ph.D.**  
 Executive Director  
 Center for Persons with Disabilities,  
 Utah State University



**Daniel J. Tomasulo, Ph.D.,  
 TEP, MFA, MAPP**  
 Coordinator Academic Director,  
 Core Faculty Member  
 Spirituality Mind Body Institute,  
 Columbia University



**Kelly Nye-Lengerman,  
 Ph.D. MSW**  
 Director,  
 Institute on Disability,  
 University of New Hampshire



**Patricia Wright, Ph.D., MPH**  
 Executive Director  
 Proof Positive Autism  
 Welling Alliance



**Yona Lunskey, Ph.D.**  
 Consortium Advisor  
 University of Toronto



**Angela Hassiotis, Ph.D.**  
 Consortium Advisor  
 University College London



**Alex Parrish-Valliere**  
 Grants Manager  
 Institute on Disability,  
 University of New Hampshire



**Luke Reynard, MBA**  
 Finance Officer  
 Institute on Disability,  
 University of New Hampshire

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## RESEARCH PARTNERS

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## 2023 BUDGET

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### Contributions

Contributions from January 2023 through June 2024 are included in this report. Total contributions were \$235,984 consisting of \$120,000 in cash donations and \$115,984 in-kind contributions. In-kind contributions included personnel effort, annual meeting space and support. NRC oversight and operations support is donated by the University of New Hampshire Institute on Disability. Donations received beginning in July 2024 will be reported in the FY25 NRC Annual Report.

### Expenses: Innovations in Research Awards

During the reporting period a total of \$154,199 was awarded for innovations in research. The NRC innovations in research awards exceeded contributions. Additional funds came from the previous cycle's balance.

### Expenses: Operations

Operating expenses totaled \$132,166. Operating expenses included in-kind 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.

## Funded Research Projects

The research targets for the NRC are established by the NRC Board annually.

The research priority areas are:

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.
5. Interdisciplinary and patient partnerships.

This year's round of NRC innovations in research funding was extremely productive. In total, four awards were approved by the governing board. The investigators, topics covered by their research, and study methodologies were diverse. Investigators are from Brandeis University, University of Delaware, Virginia Commonwealth University, Johns Hopkins University, and Utah State University.

Each of the applications had meaningful involvement of self-advocates. The topics of research included mental health workforce development, advocacy, quality of life, self-determination, and well-being. Methodologies of the research included surveys, qualitative interviews, observational interventions, and randomized trials. Below are a list of the awardees and research project summaries.

### **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*

The 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.

## **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.

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## **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.

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## **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.



## New NRC Partnership with the Developmental Disabilities Network Journal

The Developmental Disabilities Network Journal (DDNJ) is an open-source academic journal led by Dr. Matthew Wappett and hosted by Utah State University's Institute for Disability Research, Policy, and Practice. The broader network is comprised of organizations and programs that promote advocacy, research, and service with and on behalf of individuals with developmental disabilities and their families. Organizations represented in the network include the NRC, University Centers for Excellence in Developmental Disabilities (UCEDD), and Leadership Education in Neurodevelopmental Disabilities (LEND). The DDNJ is the networks' flagship journal.



The image shows the front cover of the Developmental Disabilities Network Journal (DDNJ)

While DDNJ primarily focuses on generating scholarship about disability systems, it also covers a broad array of topics such as disability rights, community living, and interdisciplinary research. This journal “specifically highlights programs, practices, and policies that encourage the full inclusion of people with disabilities in communities and all aspects of public life.”

Each issue of the DDNJ covers a different topic. The NRC partnered with the DDNJ on their most recent issue, addressing IDD and mental health with Dr. Joan Beasley and Dr. Luther Kalb serving as chief editors. The collection of articles represented in this special edition were designed to focus on inclusion and positive mental health. The articles that were published emphasized partnership with persons with lived disability experience. This was exemplified by articles on the Person Experiences Interview Survey and Exploring Self Determination, both of which were led by a person with a disability.

**By partnering with the DDNJ, the NRC can promote and advance our research agenda.**

For more information on the DDNJ, visit: [digitalcommons.usu.edu/ddnj/](https://digitalcommons.usu.edu/ddnj/)



**Listen to our podcast:** [ddnjauthorinsights.podbean.com/e/ep-13-joan-beasley-and-luke-kalb-mhidd-special-issue/](https://ddnjauthorinsights.podbean.com/e/ep-13-joan-beasley-and-luke-kalb-mhidd-special-issue/)

## EVENTS

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### NRC Annual Meeting, October 2023

The NRC annual meeting was held on October 17, 2023, at Kennedy Krieger Institute in Baltimore, Maryland. This invitation only forum consisted of 32 attendees from across the country.

#### **Presentation:**

Inclusive Practices in Research moderated by Dr. Andrea Caoili, University of New Hampshire

#### **Speakers:**

- Dr. Jessica Kramer, University of Florida
- Micah Peace Urquilla, University of New Hampshire
- Dr. Jill Jones, NHS Education for Scotland
- Dr. Doug McConachie, NHS Education for Scotland

#### **Respondents:**

- Prof. Tawara Goode, Georgetown University
- Dr. Richard Chapman, Virginia Commonwealth University
- Dr. Matthew Wappett, Utah State University

#### **Presentation:**

Positive Psychology Research moderated by Dr. Luke Kalb, Kennedy Kreiger Institute

#### **Speakers:**

- Dr. Dan Tomasulo, Columbia University
- Dr. Sarah Jaser, Vanderbilt University Medical Center

#### **Respondents:**

- Dr. Andrea Caoili, University of New Hampshire
- Micah Peace Urquilla, University of New Hampshire
- Dr. Patricia Wright, Proof Positive: Autism Wellbeing Alliance



The image shows a panel of seven individuals sitting at a long conference table in a meeting room. Each person has a name badge, and there are papers, notebooks, and water bottles on the table. The room has a projector screen in the background with a partially visible presentation slide,

The event concluded with a presentation on the NRC grant application process and a call for proposals for Utah State's DDNJ Special Edition. The meeting provided a platform to exchange ideas and collaborate. It exemplified the commitment of these organizations and universities to advance the well-being and inclusion of individuals with IDD.

## 2024 Annual Meeting

The next annual meeting will be held on October 16, 2024, at Kennedy Krieger Institute in Baltimore, MD.



The image shows Dr. Joan Beasley standing side by side to a taller man with his arm around her shoulder, smiling at the camera. They are in a room that appears to be a conference or meeting room. The room behind them has several tables with water bottles, papers, and lunch bags visible, and there are other people seated and interacting in the background.