

National Research Consortium on MHIDD

FY20 Annual Report | July 1, 2019 – June 30, 2020

The National Research Consortium on Mental Health in Intellectual and Developmental Disabilities (NRC-MHIDD) was first launched in 2019 by the Center for START Services. The goal is to promote research in mental health aspects of intellectual and developmental disabilities, with an emphasis on wellbeing and strength-based approaches. The Consortium is comprised of people with lived experiences, caregivers, trainees, researchers, policy experts, service providers and clinicians. Over 30 organizations across the US are represented, including several University Centers for Excellence in Disability (UCEDs), medical schools, state health departments, and service provider organizations (Appendix 1 is a full list of 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 MHIDD across the country. The Center for START Services at the University of New Hampshire Institute on Disability University/UCED 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 and providers, the NRC is committed to inclusion of self-advocates and families to help guide the research agenda and interpret the findings.

Research Priorities FY20

The research agenda was set by the NRC Leadership and Sponsorship Board. There are currently four priority areas of research, including: 1) positive psychology 2) evidenced-based interventions; 3) service disparities; and 4) accessible measures.

Leadership and Sponsorship Board



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



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



Andrea Caoli, LCSW
Director of Consortium
Operations
Center for START Services



Roberto Blanco, MD
Clinical Associate Professor
 UNC SCHOOL OF MEDICINE



John Dickerson
Chief Executive Officer
 Quillo



Tawara Goode, MA
Director
 GEORGETOWN UNIVERSITY
Center for Child and Human Development



Melanie Hecker, BA
Advocate
MPA Graduate Student



Colleen Horton, MPA
Director of Policy
 Hogg Foundation for Mental Health



Cheryl Karran, LMSW
Director YAI START Programs
 YAI
Seeing beyond disability.



Susan Klick
Family Member



Pat Nobbie, PhD
Disability Policy
Engagement Director
 Anthem



Dan Tomasulo, PhD
Core Faculty
 SPIRITUALITY MIND BODY INSTITUTE



Matthew Wappett, PhD
Executive Director
 CENTER for PERSONS with DISABILITIES
Utah State University

Endorsement Partners



Human Services
Research Institute



International Advisors



Yona Lunsky, PhD,
University of Toronto
Consortium Advisor



Angela Hassiotis, MA, MD, PhD
University College London
Consortium Advisor

FY20 Budget

Contributions

The National Research Consortium's full operating budget for FY20 was \$121,453. Monetary donations came from four sources (total \$72,000: YAI, Utah State University, Center for START Services, and the Hogg Foundation for Mental Health). In-kind contributions came from three other institutions (Georgetown University, Kennedy Krieger Institute, Quillo, Inc). These monies were spent across two domains: research and operations. A total of 96% of the FY20 budget was spent, leaving a balance of \$5,000 to be applied to the FY21 budget. See Appendix 2 for line item expenditures of the FY20 budget.

Expenses: Research

A total of \$44,720 funded five NRC research projects. These funds came directly from monetary donations. Each project required a match for approval. A total of \$110,000 in matching funds were provided. As a result, \$154,720 was allocated for research in FY20. See 'Funded Projects' below for details.

Expenses: Operations

A total of \$76,733 was expended for NRC operations. Operation expenses include personnel, travel, and meetings. Two board members with lived experiences were paid out of donated funds. A total of \$72,135 in funded personnel was provided by The Center for START Services, Georgetown University, and Dr. Tomasulo. Kennedy Krieger Institute donated conference meeting space, valued at \$10,000. A total of \$2,933 was expended on travel for the NRC annual meeting and \$880 for food and beverages at the meeting.

Funded Research Projects FY20

Examining cognitive accessibility and clinical applications of the VIA Character Strengths Survey.

PI: Ariel Schwartz, Postdoctoral Fellow, Boston University

Aims: 1) Examine the comprehensibility of the VIA Character Strengths Survey, when used by adults with IDD and 2) Describe how knowledge of character strengths is used in clinical practice with adults with IDD.

Total Awarded: \$11,360. Research institution's match: \$15,000

Long-term Goal: This work is designed as a first step towards deploying the VIA Survey in an electronic application, which be filled out by persons with IDD, and design of strengths-based intervention for those with IDD.

Beat It: US 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, UNC School of Medicine, NC

Aims: 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. **Total Awarded: \$17,000. Research institution's match: \$30,000**

Long-term Goal: To bring an evidenced-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

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

Long-term Goal: 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.

Using the Parent-Report Anxiety Scale (PRAS) to examine symptoms of anxiety for children with IDD enrolled in START.

PI: Jennifer McLaren, MD, Assistant Professor of Psychiatry, Dartmouth Hitchcock Medical Center, Medical Director, New Hampshire Bureau of Developmental Services, Medical Director, New Hampshire START, NH

Aims: 1) Evaluate the reliability and validity of the Parent-Report Anxiety Scale (PRAS), a brief anxiety screener, in a mixed clinical sample of youth and adults with IDD and ASD. 2) Examine the prevalence of anxiety symptoms among the large, clinical sample. 3) Identify predictors of anxiety symptoms.

Total Awarded: \$20,000. Research institution's match: \$35,000

Long-term Goal: Expand measurement of anxiety among persons with IDD. Findings will also be used to understand those at greatest risk for anxiety, to identify populations in need.

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; 3) explore predictors of mental health needs of autistic college students.

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

Long-term Goal: to increase educational supports for those with ASD in collegiate settings

FY20 Highlights and Timeline



NRC Launch

The first annual meeting of the National Research Consortium in MHIDD was held at the Kennedy Krieger Institute in Baltimore, MD. The keynote speaker was Dr. Yona Lunskey, Director of the Azrieli Adult Neurodevelopmental Centre and Professor in the Department of Psychiatry at the University of Toronto. Dr. Lunskey gave an inspiring talk on current evidenced-based programs (EBPs) around the globe for individuals with MHIDD. Dr. Angela Hassiotis, professor in the Division of Psychiatry at UCL London, joined us via zoom from London and provided an update on various efforts taking place in the UK around treating mental health conditions in IDD. Sponsoring partners, presented their interests and priorities for the field. The remainder of the day was spent in breakout sessions to foster discussion about the field and research priorities of the NRC. The six breakout areas included advancing EBPs, services and linkages, trauma informed care, crisis interventions, advocacy, and integrated care.

Each breakout group shared concrete project ideas to help advance each of the targeted areas while drawing upon the Consortium's considerable expertise. Potential projects included addressing prescriber biases, investigating Beat It and StepUp in the US, developing MHIDD trainings for employee assistance programs, and developing a public health campaign to destigmatize MHIDD.



Highlights at a Glance

2019

MARCH

CSS Identifies Funds for NRC

CSS identifies operations funds to launch NRC; Mission statement and description established; webpage developed

JULY

NRC Launch, First Board Meeting

OCTOBER

NRC Research & Networking Conference

1st Annual NRC Research & Networking Conference, Baltimore, MD; Keynote: Yona Lunskey, PhD, 40 participants from over 30 institutions

JUNE

Commitment from Board Members

3-year promise of donations to establish & implement NRC; Invitation to participate sent to network; Institutional research partnership commitments

NOVEMBER

Network survey to establish research priorities

JANUARY

NRC Board Meeting

Survey review & priority setting

MARCH

NRC Network Meeting

40 participants; presentations on externally funded and potential projects

MAY

NRC Board Meeting

Innovation Award Funding Decision
Awarded a total of \$45,000 (\$110,000 match) for five projects

2020

FEBRUARY

NRC Innovation Award RFA Solicitation

APRIL

NRC Innovation Award RFA Deadline

JUNE

COVID-19 RFA Opens; Anthem makes FY21 donation for research; FY20 Board renews membership

FY21 Planning

COVID-19 Request for Research Applications

Day-to-day life for those with MHIDD has been profoundly disrupted due to the pandemic. Loss of educational, clinical, and occupational services, social distancing, economic downturns, and the fear of infection will likely increase disparities for a group who has been historically underserved. Further, it has become clear that rates of infection and death are far higher among people with ID than the general population¹.

The NRC is seeking research applications that shed light on the impact of COVID-19 among this group and that offer solutions. The NRC will provide up to \$10,000 of support for a maximum of two projects. Project award will be made by 8/15/2020, with projects expected to begin 9/15/2020. For more information, contact Dr. Luther Kalb (kalb@kennedykrieger.org), Chair of the NRC, and Andrea Caoili (andrea.caoili@unh.edu), Director of Consortium Operations.

FY21 Budget Projections

All FY20 NRC Board members remain active in FY21 and the board welcomes a new member, Dr. Patricia Nobbie, from our newest sponsor, Anthem Inc. Total monetary contributions for FY21 is projected to be \$82,000 with in-kind contributions at an estimated \$32,500. With FY20 carry over funds \$5000, the total operating budget for FY21 is projected to be \$135,500.

Execution of Currently Funded Projects

Most research projects are underway and are proceeding as planned despite the onset of COVID-19, with the exception of one. The project titled, *Using the Parent-Report Anxiety Scale (PRAS) to examine symptoms of anxiety for children with IDD enrolled in START*, has been postponed. The anticipated start date is fall, 2020.

The NRC leadership team will monitor progress on all funded projects. Each project will also submit a 6-month report to the NRC Advisory Board. The next NRC Advisory Board Meeting will be convened on August 11, 2020.

Annual Meeting 2020

The next annual meeting will be held virtually via zoom on October 21, 2020. The keynote presentation and discussion will be provided by Tawara Goode, MA, the Director of The National Center for Cultural Competence, Center for Child and Human Development, Georgetown University. Other topics covered during the meeting will include funded project descriptions and updates, along with a PCORI funded project facilitated by PI Jessica Kramer, PhD. We will also work to establish priorities for the coming year.

References

1 Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis [published online ahead of print, 2020 May 24. *Disabil Health J.* 2020;100942. doi:10.1016/j.dhjo.2020.100942

Appendix 1

NRC Leadership Team

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

Sponsorship Board

- 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
- 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, BA, Self-Advocate, MPA Graduate Student - Albany, NY
- Colleen Horton, MPA, Director of Policy, Hogg Foundation at the University of Texas at Austin - Austin, TX
- Cheryl Karran, LMSW, Director of YAI START Programs, YAI - New York, NY, San Jose, CA
- Susan Klick, Family Member - Hartford, CT
- Patricia Nobbie, PhD, Director of Disability Policy Engagement, Anthem Inc. - Washington, DC
- Dan Tomasulo, PhD, MFA, MAPP, incoming Academic Director, Spirituality Mind Body Institute (SMB) MA Degree Program, core faculty, full-time lecturer, Department of Clinical Psychology at Teachers College, Columbia University – New York, NY
- Matthew Wappett, PhD, Executive Director & Research Associate Professor, Utah State University Center for Persons with Disabilities/UCEDD – Logan, UT

International Advisors

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

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
- L. Jarrett Barnhill, MD, DFAPA, FAACAP, Professor and Founding Director, Program on Neurodevelopmental Psychiatry, UNC School of Medicine – Chapel Hill, NC
- Jim Bedford, MD, Assistant Professor, UNC School of Medicine – Chapel Hill, NC
- Alixé Bonardi, MPA, MS, Director of IDD Services Research, Human Services Research Institute – Cambridge, MA
- 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
- 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 – Baltimore, MD
- Lisa Hovermale, MD, Psychiatrist, Maryland Department of Health - Baltimore, MD
- Diane Jacobstein, PhD, Associate Professor, Georgetown University Center for Child and Human Development/UCEDD – Washington, DC
- Jessica Kramer, PhD, OTR/L, Associate Professor, Department of Occupational Therapy, College of Public Health and Health Professions, University of Florida – Gainesville, FL
- Jennifer McLaren, MD, Psychiatrist, Dartmouth Hitchcock Clinic – Hanover, NH, Medical Advisor, Center for START Services
- Marian E. Ofonedu, PhD, LCSW, Director of Training, Maryland Center for Developmental Disabilities/UCEDD – Baltimore, MD
- Ariel Schwartz, PhD, Postdoctoral Fellow, Boston University – Boston, MA
- Kathleen Shepperd Jones, PhD, Director, University of Kentucky Human Development Institute/UCED – Lexington, KY
- Jenny Sladen, MA, Director of National Initiatives, The Arc of the United States – Washington, DC
- Marc Tassé, PhD, Director, The Ohio State University Nisonger Center/UCEDD – Columbus, OH

Appendix 2

Fiscal Year 2020 Budget and Summary of Expenditures

Donations	
Cash Donations	\$ 72,000.00
In Kind Donations	\$ 39,593.43
Total Value of Contributions	\$ 111,593.43
Expenses	
Personnel	
Personnel Expense	\$ 32,541.95
In Kind Value Subtotal Contribution (offset)	\$ 39,593.43
Total Personnel	\$ 72,135.38
Total Travel	\$ 2,933.22
Awards	
Proposal 1	\$ 11,360.00
Proposal 2	\$ 17,000.00
Proposal 3	\$ 7,000.00
Proposal 4 (*excluded from calculation- FY21 award)	\$20000*
Proposal 5	\$ 9,360.00
Awards total	\$ 44,720.00
Other	
Supplies	\$ 34.57
Service Provider - Payment	\$ 750.00
Meeting Costs	\$ 880.10
Total Other	\$ 1,664.67
Subtotal Expenses	\$ 121,453.27
FY20 Operational Budget	\$ (9,859.84)
Carryover FY19 Balance	\$ 15,000.00
FUND BALANCE	\$ 5,140.16