ANNUAL REPORT
2021

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DIRECTOR’S FOREWORD

Once again, the 2021 annual report highlights accomplishments that would not be possible without our network partners. The continuing challenges faced during a year dominated by the pandemic and its surges, served as a daily reminder of the resilience and strength in a community that works together toward the greater good. Implementation of the START model continued to expand across the country (see map below), we now work with 27 states with others states in early development. Research and evaluation of the mental health aspects of intellectual and developmental disabilities and the START model influenced our practices, and the field at large, including several peer-reviewed publications. The National Research Consortium supported important new research initiatives to promote the well-being of people with IDD and mental health service needs, and federally funded research grant work continued and expanded. Professional development offerings, an important focus of NCSS, continues to expand in reach and scope. But is has not been easy as many social justice issues remain, and the world is in turmoil. However, as I write this introduction, I remain hopeful for a better future for all of us. We are paid to think, a luxury we can never take for granted. To paraphrase Maya Angelou, it is our mission to do the best we can until we know better, and when we know better, we must do better. This requires the inclusion of the voices of those most impacted by our efforts and the wisdom to learn from each other. Hope prevails, and we are in active pursuit of a better tomorrow.

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

OUR TEAM

The National Center for START Services welcomed several new staff this year to assist with NCSS’ rapid expansion. Welcome to our new team members.

SENIOR LEADERSHIP

▶ Joan B. Beasley, PhD – Director, Research Associate Professor
▶ Andrea Caoli, LCSW – Director of Research & Quality Assurance
▶ Beth Grosso, MSW – Director of Training & Professional Development
▶ Jill Hinton, PhD – Clinical Director
▶ Ann Klein, MA – Director of Outcomes & Evaluation
▶ Anne LaForce, MA – Director of Therapeutic Coaching
▶ Jenee Lewis-Walker, PsyD, LCP – Director of Child Mental Health Services
▶ Jennifer McLaren, MD – Chief Medical Office
▶ Robert Scholz, MS, LMHC – Director of Resource Center Services
▶ Karen Weigle, PhD – Associate Director

PROGRAM IMPLEMENTATION

▶ Alyce Benson, LCSW – Associate Project Facilitator
▶ Kristal Garcia, LMSW – Associate Project Facilitator
▶ Maya Hu-Morabito, MA – Program Development Lead
▶ David O’Neal, MS, LMHC – Project Facilitator
RESEARCH & QUALITY ASSURANCE
▶ Jillaine Baker, LCSW – Associate Director of Quality Assurance
▶ Jarrett Barnhill, MD – Medical Advisor & Researcher
▶ Melanie Hecker, MPA – Research and Training Assistant
▶ Luke Kalb, PhD – Chair, Research Committee; Chair, National Research Consortium on Mental Health in IDD
▶ Sammy Klipsch – Grant Manager
▶ Ginny Reding, LPC, LMFT – Outcomes and Evaluation Support Specialist

TRAINING & PROFESSIONAL DEVELOPMENT
▶ Dan Baker, PhD – Associate Project Facilitator & Trainer
▶ Demetra Grigley – Associate Trainer
▶ Michelle Kluttz – Associate Trainer
▶ Christy Prophete, MS, MFT – Associate Trainer
▶ Sara Stanton, MA, NCC – Project Facilitator / Training Content Specialist
▶ Andrea Watkins-Cropper, MBA – Training Coordinator

OPERATING STAFF
▶ Lindsay Allsop – Communications Coordinator
▶ Mila Bohlin – Business Manager
▶ Diann Kashulines – Finance Administrator
▶ Lauren Quann, MA – Director of Operations
▶ Luke Reynard, MBA – Operations Consultant
▶ Shannon Wedge – Production Coordinator

NATIONAL CENTER FOR START SERVICES ADVISORY COUNCIL
▶ Chair: Karen Weigle, PhD, Associate Director, National Center for START Services
▶ Co-Chair: Joan Beasley, PhD, Director, National Center for START Services

CURRENT MEMBERS
▶ Dan Baker – MN
▶ Bruce Davis – TN
▶ Meg DePasquale – MD
▶ Novella Evans – MD
▶ Tawara Goode – DC
▶ Alexis Harrington – NY
▶ Kelly Hartman – IN
▶ Brenda Jackson – KS
▶ Diane Jacobstein – DC
▶ Dorota Kearney – NY
▶ Susan Klick – CT
▶ Eric Kurtz – SD
▶ Bob Lincoln – IA
▶ Mark Lutte – ME
▶ Allyson Meade – NY
▶ Lorrie Mitchell – ME
▶ Angela Munoz – CA
▶ Patricia N Robbie – DC
▶ Rachel Noell – NC
▶ Gail Paysour – VA
▶ Jill Pettinger – NY
▶ Crystal Porter – CO
▶ Ann Potoczak – NH
▶ Luke Reynard – NH
▶ Cordelia Rosenberg – CO
▶ Leslie Rubin – GA
▶ Paul Saucier – ME
▶ Larry Stang – AR
▶ Haley Turner – TX
▶ Wanda Willis – TN
▶ Louisa Wren – CO
UNH INSTITUTE ON DISABILITY

The Institute on Disability (IOD) was established in 1987 to provide a university-based focus for the improvement of knowledge, policies, and practices related to the lives of people with disabilities and their families and is New Hampshire’s University Center for Excellence in Disability (UCED). Located within the University of New Hampshire, the IOD is a federally designated center authorized by the Developmental Disabilities Act. Through innovative and interdisciplinary research, academic, service, and dissemination initiatives, the IOD builds local, state, and national capacities to respond to the needs of individuals with disabilities and their families.

THE NATIONAL CENTER FOR START SERVICES

Under the direction of Dr. Beasley, the National Center for START Services (NCSS) was developed at the UNH IOD in 2009. NCSS is dedicated to the development of professional development and training, research and evaluation, and refinement, development, and implementation of the START Model to improve services and supports for children and adults with IDD and mental health service experiences (receive mental health services/treatment due to diagnosed mental health condition and/or challenging behavior).

THE START MODEL

START is an evidence-based, humanistic, integrated health, cross-systems crisis prevention and intervention, linkage team for people with intellectual/developmental disabilities and mental health needs, and their families. Fidelity to the model requires the START team be trained and certified in the model and includes continuous reporting and analysis to ensure evidence-informed best practices across the country. First developed in 1988, the initial publication on the model was in 1990. START was cited as a promising practice to overcome mental health disparities in the 2002 Surgeon General’s Report, and by the New York State Office for Persons with Developmental Disabilities at the National Academies of Sciences, Engineering, and Medicine in 2016. Peer-reviewed and published studies report evidence of significant positive outcomes across both rural and urban settings in the context of START services.

START teams provide a highly skilled work force dedicated to strengths-based approaches, and rigorous assessment and treatment practices. Teams provide cross-systems crisis prevention and intervention planning, network partnerships, mental health assessment and coaching, 24-hour crisis response, outreach, and training. We are committed to continuous improvements in cultural and linguistic competency across our network. Patient-centered START practices are employed to actively engage a diverse community of service recipients in their own treatment in the context of their character strengths and resilience. Studies of START have found significant reduction in crisis, emergency department visits, and psychiatric hospitalizations, as well as higher service satisfaction reported by caregivers.1, 2, 3, 4, 5, 6, 7

The START Conceptual Framework developed by Jessica Kramer, PhD helps to show the mission of the model and research findings in recent years. Within the first eight months of services, on average, we have found that an individual and system of support may experience a cycle of engagement that includes 24-hour crisis response, review and revision of crisis prevention and intervention plans, and continuous assessment, dialogue and coaching within the individual’s system of support. This results in increased service system linkages and capacity to better support the individual. We have learned from the research that race, ethnicity, where you live, and your level of impairment influence these outcomes, along with health conditions and employment. Over time (approximately 12-18 months), the research shows that there is a decrease in emergency service use and increased perceived quality of care. We have found that these go hand in hand. Increased mental health stability is the result, and we have found that this continues over time. START programs have a low re-admission rate for individuals who have been discharged after receiving services in this way.

START PROGRAMS AND PROJECTS

All START programs work together as a national community of practice facilitated by the National Center. Certified START programs provide:

- Expertise in the mental health aspects of IDD
- Validated assessments, training, interventions, and ongoing dialogue with stakeholders within the context of the START model’s guiding principles
- Cross-systems crisis prevention and intervention planning
- Certified START coordination
- Therapeutic supports (resource centers and therapeutic coaching) provided by highly skilled direct support staff
- Psychopharmacology consultation
- Outreach to the person, their supports, and service providers to enhance the capacity of all
- Face-to-face, timely crisis prevention and intervention services, and 24-hour/seven-day crisis response
- Increased knowledge of MHIDD among professionals through outreach and training
- Participation in NCSS innovative training and research initiatives
START program implementation follows a three to four-year development process where NCSS provides ongoing, in-person, and virtual support in the form of START model tools, training, strategic planning, consultation, and technical assistance. This support occurs at all phases of implementation. The map shows the locations and certification status of START programs and projects in the United States at the conclusion of 2021.

NEW PROGRAMS

START Expansion Continues: In 2021, CA START expanded to serve 15 of the 21 Regional Centers across the state. The START Network also welcomed CO START Denver and PA START, Allegheny County.

LOOKING AHEAD

Systems Analyses will begin in 2022 and will include the following states/locations: Wisconsin, Maine, and Boulder, CO. START professional development training begins in Idaho in preparation for START implementation.
THE START POPULATION

EXPANSION OF THE START INFORMATION REPORTING SYSTEM (SIRS) DATABASE

The START Information Reporting System (SIRS) is a centralized web-based database used by START programs to collect and analyze data related to START service delivery. Developed in 2013, the database captures de-identified clinical and demographic information about START service users, the provision of START services, emergency service utilization, and clinical data. Currently, over 12,000 records of START service users are housed in SIRS. While changes to SIRS have been an ongoing process since its development, 2021 marked significant expansion. Changes in SIRS are a direct reflection of refinements to START clinical practice and expand the ability of programs to demonstrate what services are provided, as well as the approaches and strategies used in the context of those services. These changes will provide more robust clinical data to support START outcomes across the county.

Recent expansion includes:

► The addition of the Outreach Time Tracker with categories for outreach activities and therapeutic coaching strategies/approaches
► The addition of coaching approaches and strategies to the therapeutic coaching page
► New intake fields added to further ensure that enrollees and families can access needed supports, including:
  ▷ Access to technology that supports telehealth
  ▷ Preferred language
  ▷ Communication devices or other accommodations to enhance supports
► START crisis response service outcomes changes to clearly track crisis follow-up
► New fidelity monitoring tools
► Updated assessment tools to reflect changes to program requirements

THE START POPULATION

In 2021, START programs served 4,029 people with IDD-MH across the lifespan. At the time of enrollment, 36% were under the age of 18 and 60% resided with family. START programs serve a diverse population with over 42% of people enrolled identifying as a person of color. In addition to psychiatric conditions, over 72% of adults and 56% of children have medical co-morbidities, with neurologic, gastrointestinal, and endocrine concerns being most common.

<table>
<thead>
<tr>
<th>START POPULATION</th>
<th>NUMBER</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children (6-17)</td>
<td>1,454</td>
<td>36%</td>
</tr>
<tr>
<td>Young Adults (18-30)</td>
<td>1,749</td>
<td>43%</td>
</tr>
<tr>
<td>Adults (31-54)</td>
<td>723</td>
<td>18%</td>
</tr>
<tr>
<td>Older adults (55+)</td>
<td>103</td>
<td>3%</td>
</tr>
<tr>
<td>Total</td>
<td>4,029</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IDENTIFIED RACE/ETHNICITY</th>
<th>NUMBER</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaska Native</td>
<td>38</td>
<td>1%</td>
</tr>
<tr>
<td>Asian</td>
<td>172</td>
<td>4%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>887</td>
<td>22%</td>
</tr>
<tr>
<td>Hispanic / Latino / Latina listed as race</td>
<td>240</td>
<td>6%</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>16</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Two or more races</td>
<td>251</td>
<td>6%</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>9</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>White</td>
<td>2,335</td>
<td>58%</td>
</tr>
<tr>
<td>Unknown / declined to provide</td>
<td>81</td>
<td>2%</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>ETHNICITY</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Hispanic/Latino of any race</td>
<td>657</td>
</tr>
</tbody>
</table>
2021 NATIONAL SERVICE OUTCOMES

In 2021, 2,650 crisis calls were received. A total of 85% of those calls resulted in the person remaining in their community setting and an additional 9% returning home following a brief emergency department visit. Emergency department and in-patient psychiatric use also improved for START enrollees in 2021.

EMERGENCY SERVICE UTILIZATION PRE AND POST START ENROLLMENT

Inpatient | Emergency Dept
---|---
*Pre-enrollment* | *Post-enrollment*

DISTRIBUTION OF CRISIS CONTACTS IN 2021

Maintain Setting 85%
Psychiatric Hospitalization 3%
Emergency Department 8%
Other* 4%

*Medical admission, crisis stabilization unit, detention*
START includes a 24-hour crisis response system. With SIRS data for 1,188 START service users (mean age = 27 years) across the United States, Kalb et al. evaluated timing, outcomes, and predictors of mental health crises among those with IDD. While an increase in contacts was observed in the initial three months of enrollment (which is not surprising given service users and families are enrolled in times of need), there was a steep drop off thereafter. The figures below display these trends and the finding that few contacts happened after one year.

### DAYS UNTIL FIRST CRISIS EVENT

![Graph showing the days until the first crisis event](image)

### FREQUENCY OF CRISIS EVENTS

![Graph showing the frequency of crisis events](image)

### MENTAL HEALTH STABILITY (ABERRANT BEHAVIOR CHECKLIST)

The Aberrant Behavior Checklist (ABC) is used by START programs to monitor mental health stability over time. The ABC is conducted at intake and every six months thereafter. A total of 2,886 START service users are included since not all people had multiple administrations at the time of the analysis. Seventy-one percent of individuals had a reduction in mental health symptoms as measured by the ABC.

![Graph showing ABC data](image)

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COMPETENCY-BASED TRAINING PROVIDED TO THE START NETWORK

COORDINATOR TRAINING AND CERTIFICATION

The START Coordinator Certification Curriculum was developed to ensure that all START team members are proficient in the knowledge and skills necessary to be effective specialists in the mental health aspects of IDD and START practices. The START Coordinator Curriculum consists of three main elements: the START Coordinator Certification Course, Coordinator Training Group participation, and START coordination apprenticeship.

- **Coordinator Certification Course:** The course consists of 40+ video presentations paired with reading assignments that provide in-depth training on IDD-MH and START model approaches and tools.

- **Coordinator Training Groups:** Groups of 15-20 coordinators meet weekly for five months in these interactive learning forums facilitated by NCSS staff to deepen understanding of course content.

- **Active START Coordination:** Direct application of the START approach is vital to fully integrate the curriculum content and facilitated training group discussions into daily work. Direct support and coaching are provided to all new START coordinators as part of this apprenticeship model of practice development.

2021 START COORDINATOR TRAINING

<table>
<thead>
<tr>
<th>2021 START COORDINATOR TRAINING</th>
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</thead>
<tbody>
<tr>
<td>366 Certified START Coordinators</td>
</tr>
<tr>
<td>631 Coordinator Training Group Participants</td>
</tr>
</tbody>
</table>

START MASTER WORKSHOPS

Master Workshops conducted by the author of the START model, Dr. Joan Beasley, are provided to START programs on a regularly scheduled basis. Dr. Beasley offers in-depth explorations of key START methods and approaches for START team members. These workshops were well attended and will continue in 2022.

<table>
<thead>
<tr>
<th>MONTH</th>
<th>TOPIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2021</td>
<td>Role of START Team Members &amp; Cross-Systems Crisis Prevention and Intervention Planning</td>
</tr>
<tr>
<td>February 2021</td>
<td>Collaborating with Law Enforcement</td>
</tr>
<tr>
<td>March 2021</td>
<td>Systemic consultation and linkages</td>
</tr>
<tr>
<td>April 2021</td>
<td>The START Referral and Enrollment Process</td>
</tr>
</tbody>
</table>
START NATIONAL ONLINE TRAINING SERIES ON MENTAL HEALTH AND IDD

The START National Online Training Series on Mental Health and IDD is designed to provide innovative and topic-focused training to professionals that serve individuals who experience IDD and mental health needs. Pre-recorded trainings from this series are released once a month to the START network and other partners from September through April. Live virtual discussion sessions are hosted by NCSS on the monthly air date. The series was viewed at over 1,500 sites nationwide. More information about the National Online Training Series can be found on the NCSS website.

<table>
<thead>
<tr>
<th>MONTH</th>
<th>TOPICS &amp; PRESENTERS</th>
</tr>
</thead>
</table>
| January 2021   | Sexuality & IDD-MH  
  *Dave Hingsburger, M.Ed.* |
| February 2021  | Lost in Translation: Lessons About Moving Research in Developmental Disabilities into  
  Practice and Policy  
  *Yona Lunsky, PhD* |
| March 2021     | “Something’s Different” – Concepts of Change in Adults with IDD  
  *Julie A Moran, DO, Geriatrician/Internist* |
| April 2021     | Aligning our Practices with our Beliefs: (Re)Engaging with Families in the Context of  
  Trauma  
  *Kelly Smith, LICSW* |
| September 2021 | 2021 Virtual SNTI Poster Session Winner Presentation:  
  CA START Alta – Prevalence of Early Childhood Trauma, Adverse Childhood Experiences,  
  and Lifelong Trauma and the Impact on Behavioral Health Symptoms and Gaps in Treatment  
  in Individuals with IDD  
  *CA START Alta: Jana Cooper, AMFT and Noemi Beck-Wegner, Psy.D.* |
| October 2021   | Unjust: Race, Disability, and Criminal Justice  
  *Jennifer Sarrett, PhD*, with guest speaker panel including individuals and families with lived experience: Camille Proctor, The Color of Autism; and Candace Coleman, racial justice organizer at Chicago’s Center for Independent Living |
| November 2021  | Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and  
  Developmental Disabilities  
  *Jennifer McLaren, MD, Andrea Caoili, LCSW, and Melanie Hecker, MPA* |
| December 2021  | Special Presentation  
  Transforming Research Forum (as presented at National Research Consortium Annual  
  Meeting in October 2021)  
  *Jessica Kramer, PhD, OTR/L, Destiny Watkins, Tawara Goode, MA, Joan B. Beasley, PhD,  
  Micah Peace, Beth Grosso, MSW, and Fiorella Guerrero, MA* |
| January 2022   | Self-Advocacy and Disability Identity Development  
  *Melanie Hecker, MPA* |
| February 2022  | Part 1 of 2: Foundations of Psychology & Mental Wellness  
  *Jill Hinton, PhD* |
| March 2022     | Part 2 of 2: Point / Counterpoint – Behaviorism & Positive Psychology  
  *Dan Baker, PhD, Joan B. Beasley, PhD; Moderated by Jill Hinton, PhD* |
| April 2022     | Assessment and Intervention of Suicidality: Special Considerations for Individuals with  
  Intellectual Disability and Autism  
  *Karen Weigle, PhD & Darlene Sweetland, PhD* |
2021 START NATIONAL TRAINING INSTITUTE – START WITH MINDFULNESS: UNLOCKING OUR POTENTIAL

The 2021 Virtual START National Training Institute (SNTI) was held from May 2-5, 2021. Over 850 people across 39 states registered for this three-day event. The SNTI featured two keynote presentations, Q&A sessions, a research panel, a research poster session, and an awards ceremony. The virtual SNTI was an enormous success and received overwhelmingly positive feedback from participants.

2021 SNTI POSTER SESSIONS

The annual START Research Poster Session had 15 submissions on a wide variety of topics related to best practices in IDD-MH and START service delivery. Posters were judged by a panel selected by members of the START Research Committee.

2021 Virtual Poster Session Winners

- **1st place:** CA START Alta: Prevalence of Early Childhood Trauma, Adverse Childhood Experiences, and Lifelong Trauma and the Impact on Behavioral Health Symptoms and Gaps in Treatment in Individuals with IDD
- **2nd place:** NC West START: The Efficacy of Virtual Crisis Response During the Covid-19 Pandemic
- **3rd place:** NH START: Pivoting to Virtual Groups During a Year of Global Pandemic
- **4th place:** CA START San Diego, Westside & SCLA: Therapeutic Coaching and Covid-19

START NATIONAL TRAINING INSTITUTE AWARDS

National Center for START Services William I. Gardner Award

The National Center for START Services developed a national START Award in honor of Dr. William I. Gardner, a beloved mentor, friend, and member of the START National Training Team who passed away in 2014. The William I. Gardner Award is the National Center for START Services’ highest honor, recognizing a national leader who has made significant contributions in the effort to improve the lives of people with intellectual/developmental disabilities and behavioral health needs. The recipient exemplifies START’s mission of increasing expertise within systems of care.

2021 William I. Gardner Award Recipients

**Policy:** Professor Tawara Goode  
Director, National Center for Cultural Competence (NCCC); Director, University Center for Excellence in Developmental Disabilities, Georgetown University; Assistant Professor, Georgetown University

**Clinical:** Dr. Bruce Davis  
Director of Behavioral and Psychological Services, Tennessee Department of Intellectual and Developmental Disabilities

SNTI PARTICIPANT FEEDBACK

- 98% overall satisfaction rate
- 95% said the SNTI met their expectations
- 97% found the content of the SNTI useful, innovative, and evidence-informed
- 95% approved of the structure / schedule
- 96% would recommend the SNTI to others

“This was an opportunity to be presented with well-organized evidence and data in support of mindful practices. I found that to be especially useful and inspirational. It is one thing to know the benefits of mindfulness on an intuitive level, but quite another to see it supported by concrete data.”  
— Comment about Dr. Nirbhay Singh’s keynote presentation
LOOKING AHEAD: THE 2022 VIRTUAL START NATIONAL TRAINING INSTITUTE

The 2022 START National Training Institute will be held virtually on May 2-4, 2022. This year's theme is *The Pursuit of Happiness*. Dr. Nirbhay Singh will open the 2022 with a keynote entitled “The Search for Happiness,” followed by an opening plenary by Dr. Dan Tomasulo entitled “The Science of Hope—The Practice of Happiness.” The 2022 SNTI will feature a total of eight live breakout sessions, two additional plenary presentations (“Practices to Promote Joy” and “The Importance of Including People with Lived Experiences in IDD-MH Research”), two research panel discussions, a research poster session, awards ceremony, and special events.

PROFESSIONAL DEVELOPMENT WORKSHOPS BASED ON THE START MODEL

Professional development workshops and trainings based on START practices were implemented with:

- The Oklahoma Department of Human Services
- Continuum of Care, New Haven, Connecticut
- Maine Office of Aging and Disability

Participants included direct support providers, clinical staff, care coordinators, child welfare specialists, student interns, direct care professionals, field representatives, program specialists, supervisors, and directors.

MENTAL HEALTH ASPECTS OF IDD PROFESSIONAL LEARNING COMMUNITY FOR PSYCHIATRIST/PRESCRIBERS & PSYCHOLOGISTS (SEPTEMBER 2021-MAY 2022)

The purpose of this project is to measure the impact of a professional learning community model on participant knowledge, self-efficacy, and changes in practice behaviors in providing treatment to patients with IDD-MH. Monthly, hour-long sessions are held virtually and include a brief case presentation (10 minutes), a brief didactic presentation (15 minutes), and group discussion (35 minutes). There are currently 32 participants across 10 states who will complete session surveys and pre- and post-assessments. CMEs and APA Continuing Education credits are offered.
## COLLABORATION WITH LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES (LEND) PROGRAMS AND UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

<table>
<thead>
<tr>
<th>UCEDD / LEND PROGRAM</th>
<th>COLLABORATION AND TRAINING PROVIDED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Georgetown University LEND</td>
<td>National Online Training Series Access to Professional Development courses</td>
</tr>
<tr>
<td>University of Montana UCEDD</td>
<td>National Online Training Series</td>
</tr>
<tr>
<td>Georgia State University LEND</td>
<td>National Online Training Series Three asynchronous training modules w/ post-quiz &amp; certificate Office hours</td>
</tr>
<tr>
<td>University of New Hampshire LEND</td>
<td>NC/SH START LEND Trainee Monthly TA Access to NH START CETs &amp; DHMC multimodal clinic</td>
</tr>
<tr>
<td>Utah State University UCEDD MHIDD Training Project Sponsored by the Administration on Community Living</td>
<td>The Utah UCEDD and its partners will develop and implement a coordinated, culturally responsive, trauma-informed, cross-systems training plan to increase the capacity of direct support professionals (DSPs) and support coordinators to meet the needs of individuals with IDD-MH in Utah. As partners, NCSS will participate on the project’s advisory board, provide guidance to implement a statewide “landscape analysis,” deliver evidence-based IDD-MH training, and support project evaluation efforts.</td>
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## THE MENTAL HEALTH ASPECTS OF INTELLECTUAL/DEVELOPMENTAL DISABILITIES PROFESSIONAL DEVELOPMENT SERIES

The NCSS Mental Health Aspects of Intellectual/Developmental Disabilities Professional Development Series is an initiative designed to build expertise in professionals through instruction on evidence-based and best practices. Each course is targeted to specific roles within human service delivery to enhance the ability to provide effective services for people with IDD and mental health needs. These six-week courses, open to anyone, follow a weekly 75-minute instruction structure accompanied by discussion with all course materials provided. UNH CEUs are available to participants. There were three professional development courses offered by NCSS in 2021.

<table>
<thead>
<tr>
<th>COURSE</th>
<th>2021 TOTAL PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Aspects of IDD for Mobile Crisis Responders</td>
<td>197</td>
</tr>
<tr>
<td>Mental Health Aspects of IDD for Care Coordinators and Case Managers</td>
<td>266</td>
</tr>
<tr>
<td>Mental Health Aspects of IDD Courses for Direct Support Professionals</td>
<td>70</td>
</tr>
</tbody>
</table>

For more information about the MHIDD Professional Development Series, contact Beth Grosso, the Director of Training and Professional Development (elizabeth.grosso@unh.edu) or visit the NCSS website.

“The material is perfect for taking back and utilizing in my everyday work.”

“Easy to understand and it gave me many tools to use.”

“I appreciated the case study and being able to apply what we learned into our jobs.”

“The format, excellent presenter and post session chat opportunity made this a really fun and educational format for distance learning.”
LOOKING AHEAD:

Vanderbilt Counseling Center Staff Training
January 2022
Beginning in 2022, NCSS Staff will be training more than 35 staff at Vanderbilt's Counseling Center on the mental health aspects of IDD. Pre and post surveys and evaluations will be completed, and outcomes will be reported.

Positive Interactive Behavior Therapy (P-IBT) Certification Course led by Dr. Dan Tomasulo
August 15-19, 2022 | In-Person Event, UNH Institute on Disability, Concord, NH
This 30-hour, week-long, in-person course will provide attendees with the skills and tools needed to facilitate P-IBT sessions within their own practice settings. A multi-modal instruction approach includes didactic lectures, group discussion, demonstrations, and experiential learning through expressive writing and role-playing. Participants will receive a certificate of completion in P-IBT, confirming achievement of learning objectives and ability to facilitate P-IBT groups in their communities. This certificate will also include 3.0 UNH CEUs (30 contact hours). Intended Audience: Mental health therapists/counselors, social workers, service coordinators/care coordinators, and direct support professionals that support individuals with intellectual/developmental disabilities and mental health needs. No credentials required. Space is limited.

RESEARCH AND EVALUATION

COMPLETED PROJECTS

RECONCILING THE PAST & CHANGING THE FUTURE: ENGAGING YOUNG ADULTS WITH IDD-MH AND RESEARCHERS IN COMPARATIVE EFFECTIVENESS RESEARCH PROJECT

Patient Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award (15364 – UF)
Study Dates: 9/1/2019 – 8/13/2021
Award Amount: $249,981
PI: Jessica Kramer, PhD; Co-PIs: Joan B. Beasley, PhD & Tawara Goode

NCSS collaborated with the University of Florida and the Georgetown University National Center for Cultural Competence on this project to develop and implement Truth & Reconciliation and Transforming Research Forums to provide a structured context that begins the process of 1) reconciling past and current harms and exclusion; and 2) learning new approaches that support attitudinal and behavior change among all stakeholders, which is the catalyst for meaningful partnerships for comparative effectiveness research (CER). The goal was to support people with the lived experience of IDD-MH, their families, and researchers to learn how to partner in the conduct of research, specifically CER.

A website is available and was recently launched to provide more details about Truth & Reconciliation Forums in IDD (https://centerforstartservices.org/Truth-and-Reconciliation-Project).
EXPANSION FUNDING – UNDERSTANDING THE IMPACT OF COVID-19 ON YOUNG ADULTS WITH IDD-MH AND THEIR FAMILIES: AN ANALYTICAL FRAMEWORK AND DATABASE TO IDENTIFY SERVICE EXPERIENCES & OUTCOMES ACROSS DIVERSE POPULATIONS IN REAL TIME

Enhancement Award Amount: $139,999

Many public health crises have a disparate impact on marginalized populations including sub-groups at the intersection of race, ethnicity, and disability. This PCORI-funded project leveraged the existing infrastructure of the Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research Project. NCSS collected real-time data to document the incidence and effect of Covid-19 and mental health service use during the Covid-19 crisis. This project provides a framework to analyze mental health service use and outcomes before and after the onset of Covid-19. This unique and valuable source of information informs interventions and supports for this vulnerable and underserved population. The analytical framework will be broadly disseminated so that all researchers examining the impact of Covid-19 on mental health will consider the convergence of cultural contexts and intersectionality on observed outcomes.

SELF-ADVOCATE PERSPECTIVE

INTEGRATED MENTAL HEALTH TREATMENT GUIDELINES FOR PRESCRIBERS IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Melanie Hecker, MPA, Autistic Self-Advocate

For a long time, the medical field lacked any clear guidelines on how to assess, treat, and interact with patients with both a developmental or intellectual disability and mental health challenges. To address this, The National Center for START Services was awarded a grant from the WITH Foundation to develop Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities. This comprehensive guide includes:

- How to assess patients with IDD/MH
- Prescribing considerations both in and out of crisis
- Overviews of various psychiatric disorders and how they may manifest in people with IDD
- Best practices for communicating with people with IDD and their families
- Tips for setting up waiting rooms and mitigating sensory issues

As someone with the lived experience of both being autistic and having mental health issues, I was very happy to be able to participate in the creation of a resource that would have been helpful for me growing up. When I was younger, it was common for medical providers to not know how to communicate and interact with me. Very often they would dismiss anything I had to say, use language that I did not understand, speak to my mother without addressing me, or misinterpret my language as “manipulative”. If these providers had access to our guide section on communicating with patients with IDD and their family members, they might not have made these mistakes. Similarly, if my medical providers were able to access the guide section on sensory considerations, they might not have been so puzzled when I had strong adverse reactions to being unexpectedly touched. The existence of these guidelines will mean that the people with developmental disabilities who come after me will have better experiences across the board.

To develop this guide, our research team gathered a wealth of qualitative and quantitative data. Focus groups were held with self-advocates, families and caregivers, prescribers, and non-prescribing clinicians. These groups also completed surveys. Both the focus groups and surveys were designed to collect data on what has gone well for individuals, families, and clinicians, what has not gone well, and what can be improved in medication prescribing. This data informed our team on what types of material to include in the guide, as well as the details on each guide section.
The IDD-MH Prescriber Guidelines is frequently downloaded and accessed through the NCSS website. It is available free of charge and is used as the basis of training and professional development opportunities including topics covered as part of the START Medical Directors Practice Group. The research team extends appreciation to all who contributed to the development of this valuable resource. The next step is to develop a companion training curriculum for medical students, a project that is underway in 2022.

CURRENT PROJECTS

EVALUATION OF TELEHEALTH SERVICES ON MENTAL HEALTH OUTCOMES FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Patient Centered Outcomes Research Institute (PCORI)

Study Dates: 11/1/2021 – 10/31/2026
Project Budget: $4,864,236
PI: Joan B. Beasley; Co-PIs: Jessica Kramer, PhD, & Luke Kalb, PhD

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 crisis prevention program to a telehealth-delivered 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.

EDUCATING MEDICAL TRAINEES ON MENTAL HEALTHCARE AND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Sponsor: The WITH Foundation
Study Dates: November 2021 – October 2022
Award Amount: $50,000
PIs: Joan B. Beasley, PhD; Andrea Caoili, LCSW

This study will evaluate an evidence-informed, easy to use training curriculum in IDD-MH for medical trainees that is a companion resource to the recently developed, Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities (also known as the IDD-MH Prescribers Guidelines). The proposed curriculum will go beyond mental health pharmacologic treatment and focus on integrated healthcare. Training content will be developed in consultation with contributing authors of the IDD-MH Prescriber Guidelines who are experts in primary health, psychiatry and mental health treatment as well as family members and self-advocates.

NATIONAL RESEARCH CONSORTIUM ON MHIDD

The National Research Consortium on Mental Health in Intellectual and Developmental Disabilities (NRC) was first launched in 2019 by the National Center for START Services (NCSS). The goal of the NRC is to promote research in mental health aspects of intellectual and developmental disabilities, with an emphasis on well-being and strengths-based approaches. The NRC is comprised of people with lived experiences, caregivers, trainees, researchers, policy experts, service providers, and clinicians. Over 30 organizations across the United States are represented, including several University Centers for Excellence in Disability (UCEDs), medical schools, state health departments, and service provider organizations. 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.
2021 RESEARCH PRIORITIES

The consortium aims to promote equity and inclusion, build a national community of practice and international partnerships, and create a vehicle for information dissemination. The research agenda for 2020-2021 was set by the NRC Leadership and Sponsorship Board. There are currently five priority areas of research:

1. Positive psychology and strengths-based practices
2. Evidence-based interventions to promote well-being
3. Participatory approaches
4. Cultural and linguistic competence
5. Interdisciplinary and patient partnerships

The NRC has funded a total of six projects since its inception. Additional information about the projects, membership, the board, and how to become involved can be found at https://centerforstartservices.org/mhidd-national-research-consortium.

NRC FUNDED RESEARCH INNOVATION PROJECTS

<table>
<thead>
<tr>
<th>RESEARCH PROJECT</th>
<th>PROJECT INVESTIGATOR</th>
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<tbody>
<tr>
<td>Using Mixed-Reality Simulation to Train School-based Mental Health Professionals how to Support Students with Developmental Disabilities with Co-occurring Mental Health Concerns</td>
<td>Emily Graybill, PhD, Director, Center for Leadership in Disability, Georgia State University</td>
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<tr>
<td>Beat It: U.S.-Based Pilot Evaluation of the Behavioral Activation Intervention, Beat It, for Young Adults with ID</td>
<td>Roberto Blanco, MD, UNC School of Medicine, NC</td>
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<td>Examining Cognitive Accessibility and Clinical Applications of the VIA Character Strengths Survey</td>
<td>Ariel Schwartz, Postdoctoral Fellow, Boston University</td>
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<td>Examining the Mental Health of Autistic College Adults</td>
<td>Brian Freedman, PhD, Senior Associate Director, University of Delaware Center for Disability Studies, DE</td>
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<td>Positive Mental Health and Autism Spectrum Disorders</td>
<td>Luke Kalb, PhD, Kennedy Krieger Institute, Johns Hopkins University, MD</td>
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<td>Psychological Flexibility in Adults with ASD: Psychological Distress in the Context of Covid-19</td>
<td>Ty B. Aller, PhD, LMFT, Utah State University Center for Persons with Disabilities/UCEDD</td>
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PUBLICATIONS AND PRESENTATIONS

PEER REVIEWED PUBLICATIONS


PRESENTATIONS

Hinton, J.E. (November 2021). Trauma in Childhood [Virtual presentation]. ThinkDIFFERENTLY & Department of Behavioral and Community Health. Dutchess County, NY.

Weigle, K.L. (October 2021). Operation of the START program [Virtual presentation]. Baylor College of Medicine 22nd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care.

Weigle, K.L. (October 2021). Improving mental health outcomes for individuals with intellectual disabilities: What works [Virtual presentation]. Baylor College of Medicine 22nd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care.


