ANNUAL REPORT 2020
July 1, 2019 - December 31, 2020
Director’s Foreword

The Center for START Services 2020 Annual Report highlights achievements which would not be possible without our network partners. During this very challenging time, it has been an honor and privilege to be part of this important effort. Implementation of the START model continued to expand across the country and we welcomed teams in California, Tennessee, and Maryland with more teams online for development soon. 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. PCORI funding and our partnerships with the University of Florida and Georgetown allowed us to learn more about the experiences of families during the COVID crisis, and to improve our practices moving forward.

Our Team

The Center for START Services welcomed several adjunct staff this year to assist with CSS’ rapid expansion both in program and professional development. Welcome to our new team members.

Leadership Team

Joan B. Beasley, PhD - Director, Research Associate Professor
Karen Weigle, PhD - Associate Director
Jill Hinton, PhD - Clinical Director
Anne Marie Ashford, MBA - Business Manager
Andrea Caoili, LCSW - Director of Research & Quality Assurance
Jennifer McLaren, MD - Chief Medical Officer
Jarrett Barnhill, MD - Medical Advisor
Robert Scholz, MS, LMHC - Director of Resource Center Services
Anne LaForce, MA - Director of Therapeutic Coaching
Ann Klein, MA - Director of Outcomes & Evaluation
Beth Grosso, MSW - Director of Training
Luke Reynard, MBA - Operations Consultant

Project Facilitators & Trainers

Dan Baker, PhD - Associate Project Facilitator & Trainer
Jillaine Baker, LCSW - QA & Training Coordinator
Alyce Benson, LCSW - Associate Project Facilitator
Kristal Garcia, LMSW - Associate Project Facilitator
Melanie Hecker, MPA - Research and Training Assistant
Maya Hu-Morabito, MA - Project Manager
Luke Kalb, PhD - Chair, Research Committee, Chair, National Research Consortium on Mental Health in IDD
David O’Neal, MS, LMHC - Project Facilitator
Christy Prophete, MFT - Associate Project Facilitator
Ginny Reding, LPC, LMFT - Outcomes and Evaluation Support Specialist

Operating Staff

Diann Kashulines - Contract & Finance Administrator
Shannon Wedge - Online Events & Website Coordinator
Lindsay Allsop - Communications Coordinator

Joan B. Beasley, Ph.D.
Research Associate Professor
Director, Center for START Services
Institute on Disability/UCED
University of New Hampshire
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 Center for START Services

Under the direction of Dr. Beasley, the Center for START Services (CSS) was developed at the UNH IOD in 2011. CSS is an organization of experts in the mental health aspects of IDD that develop innovative IDD-MH training programs, conduct research, and facilitate the development of START programs across the country. CSS assists regional and statewide START programs with program design, training and tools of the START model, data collection and on-going evaluation of outcomes, technical support, and best practices in the MH aspects of IDD.

START National Advisory Council

<table>
<thead>
<tr>
<th>Name</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dan Baker</td>
<td>MN</td>
</tr>
<tr>
<td>Bruce Davis</td>
<td>TN</td>
</tr>
<tr>
<td>Meg Depasquale</td>
<td>MD</td>
</tr>
<tr>
<td>Novella Evans</td>
<td>TX</td>
</tr>
<tr>
<td>Tawara Goode</td>
<td>DC</td>
</tr>
<tr>
<td>Kelly Hartman</td>
<td>IN</td>
</tr>
<tr>
<td>Brenda Jackson</td>
<td>DC</td>
</tr>
<tr>
<td>Diane Jacobstein</td>
<td>DC</td>
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<tr>
<td>Susan Klick</td>
<td>CT</td>
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<tr>
<td>Eric Kurtz</td>
<td>SD</td>
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<tr>
<td>Tracy Levesque</td>
<td>RI</td>
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<tr>
<td>Lauren Libero</td>
<td>CA</td>
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<tr>
<td>Bob Lincoln</td>
<td>IA</td>
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<tr>
<td>Allyson Mead</td>
<td>NY</td>
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<tr>
<td>Lorrie Mitchell</td>
<td>ME</td>
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<tr>
<td>Angela Munoz</td>
<td>CA</td>
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<tr>
<td>Pat Nobbie</td>
<td>DC</td>
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<tr>
<td>Rachel Noell</td>
<td>NC</td>
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<tr>
<td>Gail Paysour</td>
<td>VA</td>
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<tr>
<td>Jill Pettinger</td>
<td>NY</td>
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<tr>
<td>Ann Potoczek</td>
<td>NH</td>
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<tr>
<td>Cordelia Rosenburg</td>
<td>CO</td>
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<tr>
<td>Leslie Rubin</td>
<td>GA</td>
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<tr>
<td>Paul Saucier</td>
<td>ME</td>
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<tr>
<td>Larry Stang</td>
<td>AR</td>
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<tr>
<td>Haley Turner</td>
<td>TX</td>
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<tr>
<td>Wanda Willis</td>
<td>TN</td>
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<tr>
<td>Louisa Wren</td>
<td>CO</td>
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</tbody>
</table>

START Model

START is a community-based crisis prevention & intervention service model for individuals age 6 and older with intellectual and developmental disabilities (IDD) and mental health service needs (IDD-MH). First developed by Dr. Joan Beasley in 1988, START was cited as a best practice in the US Surgeon General's Report (2002) and more recently at the National Academy of Sciences, Engineering and Medicine (2016). START clinical teams provide in-person mental health assessment and 24-hour crisis response, along with outreach, and therapeutic coaching/support using in-person and telemental health methods. Patient-centered START practices are employed to facilitate engagement of service recipients with IDD-MH in treatment, including those with significant delays in cognitive, communication, and social functions. Studies of START have found significant reduction in crisis, emergency department visits and psychiatric hospitalizations, and higher service satisfaction reported by caregivers.1-3

References

All START programs work together as a national community of practice facilitated by CSS. START programs have been developed in many states across the U.S. with a goal of positive systems change and local capacity building in each location.

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 intervention and prevention planning
- Certified START coordination
- Psychopharmacology consultation
- Therapeutic supports (resource centers and therapeutic coaching) provided by highly skilled direct support staff
- Outreach to the person, their supports, and service providers to enhance the capacity of all
- Face-to-face, timely crisis prevention and intervention services, 24hr/7day crisis response
- Increased knowledge of MHIDD among professionals through outreach & training
- Participation in CSS innovative training and research initiatives

START program implementation follows a 3-year development process for clinical teams and a 4-year process for programs that include START clinical teams and START therapeutic centers. CSS provides ongoing, in-person, and virtual support in the form of START model tools, training, strategic planning, consultation, and technical assistance to START programs. This support occurs at all phases of implementation. The map shows the locations and certification status of START programs and projects in the US at the end of 2020.

Program Certifications
(*Program certifications occurred virtually from March-December due to travel restrictions.)

- First time certified START programs: New Hampshire, NY Region 4 Triborough, NY Region 4 Richmond Kings.
- Program certification renewals: NC START Central, East and West; Texas START, I-START, NY Region 1, NY Region 3

Pictured above: Iowa START team celebrating their virtual certification renewal review
New Programs

- **CA START San Diego** and **San Andreas START** have begun year 2 of operations and have expanded within their regions in recent months. Additional CA START programs in the regions supported by the Alta Regional Center, East Bay Regional Center, South Central LA Regional Center, and Westside LA Regional Center began implementation and training in 2020.

Pictured left: San Andreas Regional Center and START staff with CSS team members

Pictured right: San Diego START Clinical Team

- **Maryland START** - Statewide START program implementation is now underway under the supervision and direction of the Maryland Developmental Disabilities Administration.

- **Maine Office of Aging and Disabilities Services (OADS)** - Clinical consultation and IDD-MH training based on START philosophy and best practices, and access professional development training series.

- **Continuum of Care Connecticut** - START coordinator training & certification within a private provider.
In 2019, hurricanes devastated much of the east coast of the United States and resulted in extensive flooding, especially in North and South Carolina, greatly impacting START service users, families, network partners and START staff. This natural disaster prompted the development of a National START Emergency Committee (EMC), convened to help our network partners.

The EMC is now a national forum for START network partners designed to provide comprehensive, interdisciplinary support to START service users, families, providers, and START teams in response to emergencies. The EMC is committed to developing a framework for rapid mobilization across the START network, building on linkages, available resources, expertise, innovation, and collective intelligence. The committee's role is to build the capacity of the START network to respond to any crisis that may impact service users, families, and members of our network.

The diagram demonstrates the application of the START tertiary care approach to emergency preparedness.

The EMC was instrumental in START’s national response to COVID-19 and the CA wildfires. Emergency shelters needed resources and training materials to aid in the effective support of persons with IDD. Volunteers from the EMC developed brief information sheets that were distributed to CA Regional Centers and shelters. In partnership with Quillo, Inc, EMC volunteers also created a library of brief 1-minute instructional and motivational videos that are available on the Quillo platform and their YouTube Channel.

Throughout the pandemic, the committee has engaged with START teams in distributing public health information to people with IDD and their families, developing tools and resources and providing guidance for START programs to develop emergency preparedness plans in collaboration with community partners. In addition, the team is currently working with teams to develop plans for the transition back to in-person supports. Information and resources can be found in the Resources area of the Center for START Services website: [www.centerforstartservices.org/Resources/EMC](http://www.centerforstartservices.org/Resources/EMC).
START’s Response to the COVID-19 Pandemic

Like many across the country, persons with IDD and their families are at high risk of mental health related distress associated with the pandemic. The Center for START Services and the National START Network committed to supporting the IDD community through this public health crisis.

At the onset of the COVID-19 pandemic, CSS rapidly and strategically initiated the development of telemental health crisis support protocols across the START network (initiated in March 2020). Telemental health is identified as an evidence-based method to delivering mental health services and supports.\(^1\) A series of virtual meetings with START program directors, administrators, funders, and stakeholders were held to review the telemental health protocols, and revisions to the SIRS database were made to accurately capture START telemental health service delivery.

Throughout the pandemic, CSS provided a vehicle for START programs to share resources, provide plain language information and training about COVID-19, therapeutic supports, clinical services, and crisis response using telemental health methods. Over 97% of the START population active at the time of the pandemic received some telemental health services.

In addition to planned clinical services, START teams continued to provide crisis response. The average number of START calls per month increased by about 25 calls when compared to pre-COVID times. The majority (78%) of START crisis contacts resulted in the person maintaining their current setting without more intensive emergency services.

COVID Family Interviews

In response to the COVID crisis, Dr. Beasley and Andrea Caioili developed and distributed a survey for START teams. START program staff completed over 1700 brief interviews with family caregivers using the CSS COVID Family Interview Tool to evaluate the impact of the pandemic and identify unmet needs. Interview data helped inform the START network about the impact of COVID-19 on family caregivers and START services. START teams developed targeted supports based on the unique needs of families they serve, such as access to technology, coordination of educational, mental health and/or IDD services, basic needs (food, housing, etc.), resources, materials, and other methods designed to reduce burden for family caregivers. Surveys showed that disruptions in education, medical, IDD, and mental health supports greatly impacted families, and 20% of family caregivers lost employment. In addition, 4% had an immediate family member diagnosed with COVID. Family caregivers were asked to provide additional feedback to START coordinators in response to the question: “What else do service providers need to know?” Responses are part of a larger analysis of the impact of the COVID-19 pandemic on family caregivers in process that is expected to be published next year.

Responses to “What else do service providers need to know?”

“START is doing a good job helping us when we are in crisis and has helped us by attending psychiatrist appointments to help with medication reduction.”

“The Zoom meeting with START was awesome and they are using the techniques learned in the Zoom meeting as interventions with A.”

“START has been very helpful during this time by providing consistent support over the phone and checking in every week.”

“START is readily available and is doing the best they can to make us feel supported through this mess.”

“Not everyone has access to computers or know how to use them.”

“We are all getting by the best we can.”

“START is of great help, before, during and I’m sure after COVID.”

In addition to the modification of protocols for START programs, CSS also initiated the development of a COVID-19 Resource page on the CSS website, which is used by START programs and community stakeholders nationwide. As we move into 2021, the national network will focus on ways to assure that public health information about the COVID-19 vaccine, where and when to access it, and other resources continue to be accessible to people with IDD & their families.

National START Population

New Additions to the START Information Reporting System (SIRS)

The START Information Reporting System (SIRS) is the primary tool used for collecting and analyzing data related to the provision of START services. SIRS is used by all START programs and collects basic demographics, services provided, therapeutic and emergency service utilization, and clinical outcomes. SIRS is reviewed for revisions bi-annually. Three primary revisions were completed in 2020:

1. The START Plan Version 2, an assessment developed for START use was built in SIRS. The START Plan captures biopsychosocial factors that impact mental health stability such as mental health symptoms and acuity, family/caregiver stress, cultural considerations, relationships, and quality of life.
2. To address the need for integrated models of care, SIRS also now tracks service users’ access to primary, dental, and specialty medical care.
3. As part of CSS’s COVID-19 response, telehealth fields were added to SIRS to track services provided by START programs using telehealth platforms.

Looking ahead: In 2021, SIRS will be further expanded to include fields for identified character strengths of individuals supported and a regular process for reviewing and highlighting those strengths.

The START Population

The population of START service users continues to be more vulnerable than the general population of persons with IDD with 38% diagnosed with moderate to severe ID. In addition, 93% are diagnosed with one or more mental health condition. It is important to note that 55% of enrollees are diagnosed with ASD and 62% has one or more chronic health conditions.

<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>25</td>
<td>1%</td>
</tr>
<tr>
<td>Asian</td>
<td>179</td>
<td>4%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>875</td>
<td>20%</td>
</tr>
<tr>
<td>Hispanic/Latino/Latina</td>
<td>706</td>
<td>16%</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>18</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Mixed Racial</td>
<td>41</td>
<td>1%</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>11</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>White</td>
<td>2353</td>
<td>53%</td>
</tr>
<tr>
<td>Unknown/declined to provide</td>
<td>209</td>
<td>5%</td>
</tr>
</tbody>
</table>

START teams have worked to gain a better understanding of the LGBTQia2 community, gender identity, and sexual identity. This has included seeking additional training and working with communities to broaden their understanding of the language and nuances of the spectrums of gender identity and sexual identity, as well as their intersection with the IDD community.

Race, Ethnicity, and Culture

In 2020, 40% of individuals enrolled in START programs identified as non-white. To fully support communities, including many for whom English is a second language, START programs actively recruit multi-lingual coordinators. Over 40% of START coordinators in CA, NY, and TX are bi-lingual including one entirely bi-lingual team serving El Paso County, TX. START tools and assessments are available in Spanish and several teams are in the process of developing intake/assessment activities for threshold languages in their regions, including Chinese (Cantonese and Mandarin), Vietnamese, Spanish, and Tagalog.

START teams have worked to gain a better understanding of the LGBTQia2 community, gender identity, and sexual identity. This has included seeking additional training and working with communities to broaden their understanding of the language and nuances of the spectrums of gender identity and sexual identity, as well as their intersection with the IDD community.
COVID-19 START Telemental Health Outcomes During COVID-19

94% of START service users active during the COVID-19 pandemic (n=3700) received START telemental health services. The average number of START crisis contacts by month increased by 25 calls.

Emergency Service Utilization

While crisis contacts per month increased, disposition remained consistent, with 77% of all calls resulting in the person maintaining their setting.

Distribution of crisis contact outcomes in 2019 and 2020

<table>
<thead>
<tr>
<th>Outcome</th>
<th>2019 (%)</th>
<th>2020 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric Admission</td>
<td>75%</td>
<td>77%</td>
</tr>
<tr>
<td>Utilized ED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintain Setting</td>
<td>15%</td>
<td>18%</td>
</tr>
<tr>
<td>All other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

START Crisis Contacts

April 1 - December 31 in 2019 and 2020:

<table>
<thead>
<tr>
<th>Time period</th>
<th>2019</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total calls (n)</td>
<td>2359</td>
<td>2915</td>
</tr>
<tr>
<td>Average monthly call (n)</td>
<td>261/mo.</td>
<td>291/mo.</td>
</tr>
<tr>
<td>% Conducted via telemental health</td>
<td>--</td>
<td>88%</td>
</tr>
</tbody>
</table>

Mental Health Stability (Aberrant Behavior Checklist)

The Aberrant Behavior Checklist (ABC) is used by START programs to monitor stability over time. The ABC is conducted at intake and every 6 months thereafter. A total of 3,289 START service users are included since not all cases had multiple administrations at the time of the analysis.

Service Experiences (START Plan)

CSS launched the START Plan Version 2 in 2020 and added the assessment to SIRS to track changes over time. The START Plan, completed quarterly, is designed to evaluate the MH stability of START service users and caregiver satisfaction with services. START plan responses from caregivers were analyzed for changes between initial intake and follow-up visits (n=600). The greatest improvement in the initial 6 months of START services was found in the level of stress, availability of providers to assist in a crisis, and the level of confidence of caregivers to assist in times of difficulty. A more detailed analysis will be available in 2021.

<table>
<thead>
<tr>
<th>START Plan questions (n=600)</th>
<th>Visit 1-Intake</th>
<th>Visit 2</th>
<th>Visit 3</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>How stressful has it been caring for the individual?</td>
<td>2.2</td>
<td>1.8</td>
<td>1.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>How confident are you in assisting the individual in times of difficulty?</td>
<td>1.4</td>
<td>1.2</td>
<td>1.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Are out-patient providers available if the individual is experiencing challenges?</td>
<td>1.4</td>
<td>1.1</td>
<td>1.1</td>
<td>.001</td>
</tr>
<tr>
<td>Are the MH services the individual is receiving convenient?</td>
<td>1.6</td>
<td>1.4</td>
<td>1.3</td>
<td>.007</td>
</tr>
<tr>
<td>Are providers available to you during a crisis?</td>
<td>1.8</td>
<td>1.4</td>
<td>1.4</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
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 behavioral 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 apprenticeship in START coordination.

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.

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.

Coordinator Training Groups
Groups of 15-20 coordinators meet weekly for 5 months in these interactive learning forums facilitated by CSS staff to deepen understanding of course content.

Related Statistics:
- 322 Total number of certified START Coordinators
- 446 Total number of Coordinator Training Group participants
- 313.5 Total live facilitated training session time

Therapeutic Coaching Training Groups
Therapeutic Coaching Training Groups were recently launched to consistently apply best practices and methods in coaching. There were 2 groups held in 2020, training a total of 41 participants. These training groups will continue in the coming year and beyond. More detailed information will be available in next year’s report.

START Practice Groups
Practice groups are national communities within the START Network organized around START team roles, professional disciplines, and specific topics of interest. They are designed to facilitate active learning communities where members can connect with others from across the country in similar roles and remain informed about best practices regarding both START implementation and IDD-MH topics. Groups meet regularly (one per month or bi-monthly). Each group is facilitated by CSS clinical staff and occasionally features invited speakers and special guests.

CSS practice groups include:
- Clinical Directors Practice Group, facilitated by Jill Hinton, PhD
- Children’s Practice Group, facilitated by Karen Weigle, PhD
- Resource Center Directors Practice Group, facilitated by Bob Scholz, MS, LMHC
- Medical Directors Practice Group, facilitated by Karen Weigle, PhD and Jennifer McLaren, MD
- Team Leaders Practice Group, facilitated by David O’Neal, MS, and Alyce Benson, LCSW
- Program Director Practice Group, facilitated by Andrea Caoili, LCSW and Alyce Benson, LCSW
- Certified Coordinator Network, facilitated by Karen Weigle, PhD
Competency-Based Training Provided to the START Network

START Virtual Orientation Series & Master Workshops

To help launch new programs a virtual series was provided by CSS aimed at orienting new START programs and their network partners to the core principles and approaches of the START model. The first orientation series was developed for the state of California with three consecutive half-day sessions in August, October, and December.

Master Workshops were provided to programs in New York and California by the author of the START model, Dr. Joan Beasley, on a regularly scheduled basis. Dr. Beasley offers in-depth explorations of key START tools and approaches for START team members. Participation has been excellent, and the workshops will continue in 2021.

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 CSS on the monthly air date. The series was viewed by over 1500 sites nationwide.

<table>
<thead>
<tr>
<th>September</th>
<th>Grief &amp; Bereavement in Individuals with IDD; Katy Stratigos, MD, NY START Region 4 Triborough Medical Director</th>
</tr>
</thead>
<tbody>
<tr>
<td>October</td>
<td>START Research: 2019 START National Training Institute Poster Session Winners; NY START Region 4 Triborough: Caroline Schau, Emily Weinrebe, Katy Stratigos; NY START Region 4 Richmond: Sharon Cyrus-Savary, Corey Fisk, Alexa Eugene; NH START: Val Tetreault, Samantha Field, Justin Smith, Sara Greenstein</td>
</tr>
<tr>
<td>November</td>
<td>Guidelines for Psychotropic Medication Treatment &amp; Polypharmacy: Why Don’t We Practice What We Preach? Lauren Charlot, PhD, Developmental Psychologist</td>
</tr>
<tr>
<td>January</td>
<td>Supporting Purpose and Meaning in the Lives of Individuals with IDD-MH; Michael Smull, The Learning Community for Person Centered Practices and Support Development Associates. Discussants: Dr. Jill Hinton, Center for START Services Clinical Director, and Dr. Dan Tomasulo, Core Faculty, Spirituality Mind Body Institute, Columbia University Teachers College</td>
</tr>
<tr>
<td>February</td>
<td>PERMA: The Family Perspective; Alyce Benson, LCSW, CSS Project Facilitator; Featuring Nicholas &amp; Merv Barrett; Juston Free &amp; LaVada Carnes; Kimberly Laster; Crystal &amp; Tra St. Pierre</td>
</tr>
<tr>
<td>March</td>
<td>Trauma’s Impact on Cognitive &amp; Emotional Development in Individuals with IDD; Stefanie Griffin, PhD, Clinical Neuropsychologist, NH START &amp; CSS expert consultant, and Sherm Fox, MD, Psychopharmacologist, NH START &amp; CSS Consulting Psychiatrist</td>
</tr>
<tr>
<td>April</td>
<td>Exploring the Overlap of Autism, Sexuality, &amp; Gender-Identity Difference; Dan Shapiro, MD, Developmental and Behavioral Pediatric Consultant</td>
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Looking ahead: The National Training Series has been proposed to be part of LEND programs at Georgia State University and Georgetown University UCEDs in addition to the University of Montana’s Rural Institute on Inclusive Communities currently underway. CSS continues to monitor the quality of content presented in all training forums.
START National Training Institute

During the COVID-19 pandemic, the Center for START Services hosted a no-cost Virtual START National Training Institute (SNTI) from May 4-May 6, 2020 with over 400 participants. This three-day event featured two keynote presentations, Q&A sessions, a research panel, the premiere of the START documentary film (“Now We Have Hope: The Strength of the START Community”) with a panel discussion, a research poster session, and an awards ceremony. The virtual SNTI was an enormous success and received overwhelmingly positive feedback from participants.

The annual START Research Poster Session had 10 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 the START Research Committee.

2020 Virtual Poster Session Winners

- **1st Place** -  START Therapeutic Coaching as a Suicide Prevention Tool for Individuals with IDD in the Era of COVID-19. **NC START Central:** Meredith Dangel, MA, Maggie Robbins, MA, LCAT, RDT, Remy Jodrey, MS, LCMHCA
- **2nd Place** - The Use of Mindfulness to Promote a Trauma Informed Care Environment: A Case Study. **NY START Region 5:** Alyse Scura, LMHC, Denise Bronzino, PhD
- **3rd Place** (tie) - Breathe In... Breathe Out... Now We're in the Here and Now: Incorporating Mindfulness & Sensory Integration Activities at the Resource Center. **NC START West:** Anne Doucette, PhD, Laura Shea, MA, Boyce Smith, LCMHC; **Caregiver Support Group. NC START East:** C. Shane Miller

Center for START Services William I. Gardner Award

The 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 Center for START Service's 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.

**2020 William I. Gardner Award Recipient: Liz Weintraub.** Liz Weintraub has a long history of leadership in self advocacy and has held many board and advisory positions at state and national organizations. She is a full-time member of the AUCD’s policy team as a Senior Advocacy Specialist and is also the host of Tuesdays With Liz: Disability Policy for All, where she attempts to make policies in accessible language, so policies are accessible to all.

Liz served as a Fellow for Senator Casey of Pennsylvania in 2018. Also in 2018, she told the story of her personal experience as a woman with disabilities as she testified before the Senate Judiciary Committee about the potential implications of a Kavanaugh confirmation to the civil rights of people with disabilities. You can read her submitted written testimony and watch her oral testimony on AUCD’s website.

Prior to coming to AUCD, Liz worked for the Council on Quality & Leadership (CQL). She is an alumnus of the LEND training program at the Center for Leadership in Disability at Georgia State University and was a past chair of the Maryland Developmental Disabilities Council, which she is rejoining for another term. Liz has received numerous awards, recognition, and commendations for her work, and she enjoys mentoring people with disabilities.

Looking ahead: The 2021 START National Training Institute will be held May 3-5, 2021. This year’s SNTI will be held virtually and will be provided at no cost to participants. The 2021 SNTI’s theme is “START with Mindfulness: Unlocking our Potential” with keynote addresses from Dr. Nirbhay Singh and Tawara Goode. The SNTI will feature 4 breakout sessions, a research panel discussion, research poster session, awards ceremony and special events.
Georgia Statewide Training

Based on a service system stakeholder analysis completed in February 2018, the state of Georgia’s Department of Behavioral Health and Developmental Disabilities (DBHDD) engaged CSS to provide system-wide training to increase collaboration and build capacity across the IDD-MH system. The partnership between CSS and DBHDD resulted in over 800 professionals across multiple disciplines receiving training in evidence-based practices in treatment of persons with IDD-MH. Training offerings:

- Six regional full-day on-site IDD-MH trainings
- Two full-day on-site IDD-MH trainings for medical providers
- Four 8-session PLCs focused on the needs of child and adolescents with IDD-MH
- One 8-session PLC on Positive Behavior Intervention Support
- One 14-session training and consultation forum for mobile crisis responders

START Professional Learning Communities (PLC) Based on the START Model

A Professional Learning Community (PLC) is a professional training consisting of facilitated discussion and tools to improve knowledge in the mental health aspects of IDD across local or regional systems of care. Most PLCs consist of 6-8 sessions over the span of 3 months and can be developed for MH and IDD community providers, policy/administrative stakeholders, health professionals, educators, mobile crisis teams, and other interested professionals. The PLCs offered in 2020 were:

- Rhode Island Stakeholder PLC (September 2019-December 2019)
- NY Office of Mental Health (OMH) PLC (January 2020-May 2020)

Oklahoma Support Specialist PLC on IDD-MH: This year-long course, which began in September 2020, brings together representatives from Oklahoma’s Child Welfare system departments and mental health and developmental disabilities service providers, to develop cross-systems expertise in IDD-MH.

The Mental Health Aspects of Intellectual/Developmental Disabilities Professional Development Series

The CSS Mental Health Aspects of Intellectual/Developmental Disabilities Professional Development Series (MHIDD PDS) is a new 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.

Mental Health Aspects of IDD for Mobile Crisis Responders: This course was the most widely attended, with four offerings in 2020 and a total of 386 professional participants.

Mental Health Aspects of IDD for Care Coordinators and Case Managers: Launched in September 2020 and facilitated by Dr. Joan B. Beasley, this course is designed to improve knowledge for care coordinators and case managers to successfully support children and adults with IDD and mental health service needs and their families. Speakers include family members, people with lived experiences, and experts in the field. September’s series had 110 participants and received positive feedback.

*Overall, there were high levels of interest, registration and satisfaction with both Professional Development Courses. CSS plans to offer these courses again in the coming year.*

Looking Ahead: Mental Health Aspects of IDD Course for Direct Support Professionals (launched February 2021): This live, six-session course gives Direct Support Professionals (DSPs) the knowledge, skills, and resources needed to provide individuals with IDD and mental health service needs (IDD-MH) positive, person-centered, and strengths and wellness-based supports and services. The course facilitator will demonstrate how the information reviewed during session can be applied in the day-to-day support of people with IDD-MH. The course features guest speakers with lived experience and optional 30-minute discussion sessions where participants can ask questions and further discuss course topics.
CSS was awarded a grant from the WITH Foundation to work with prescribers, family members, and service users to develop Holistic Best Practice Prescribing Guidelines in IDD-MH for Healthcare Providers. The Holistic Best Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities includes a comprehensive reference list of resources for best practices and provides key information aimed toward holistic, interdisciplinary, integrated approaches for effective mental healthcare for people with IDD. The guidelines were reviewed by prescribers across the country, the feedback was incorporated into the final version, and will be made widely available for all.

**Current CSS Research Studies**

**Holistic Best Practice Prescribing Guidelines for Healthcare Providers in IDD-MH**

*Funded by the WITH Foundation*

CSS was awarded a grant from the WITH Foundation to work with prescribers, family members, and service users to develop Holistic Best Practice Prescribing Guidelines in IDD-MH for Healthcare Providers. The Holistic Best Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities includes a comprehensive reference list of resources for best practices and provides key information aimed toward holistic, interdisciplinary, integrated approaches for effective mental healthcare for people with IDD. The guidelines were reviewed by prescribers across the country, the feedback was incorporated into the final version, and will be made widely available for all.

**PCORI Funded Projects**

About PCORI: The Patient-Centered Outcomes Research Institute (PCORI) is an organization authorized by Congress to fund comparative clinical research, or comparative effectiveness research (CER). The studies they fund are designed to produce reliable, useful information that will help patients, family caregivers, clinicians, employers, insurers, policy makers and others make better informed health and healthcare decisions. Their work is guided by a 21-member Board of Governors representing the entire healthcare community.

**Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research Project**

CSS is collaborating with the University of Florida and the Georgetown University National Center for Cultural Competence on a PCORI funded research project. The project has developed and will 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).

**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**

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 leverages the existing infrastructures of the Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research Project. Center for START Services (CSS) at the University of New Hampshire, Institute on Disability is collecting real-time data to document the incidence and effect of COVID-19 and mental health service use during this public health crisis. This project will provide a framework to analyze mental health service use and outcomes before and after the onset of COVID 19. This is a unique and valuable source of information that will inform 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. This supplemental work aligns with the goal of Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research, to increase the capacity of young adults with IDD-MH, their families, and IDD-MH researchers to partner in comparative effectiveness research (CER).
The National Research Consortium on IDD-MH

The National Research Consortium is in its second full year of operation and funded 6 studies in 2020. These studies were presented at the NRC’s second annual meeting, which was held virtually on October 21, 2020. Over 70 participants attended and engaged in dialogue about culturally competent research practices in IDD-MH. A Request for Applications for funding will be released in spring 2021. To learn more about the NRC, the stakeholder board and funded projects, visit https://centerforstartservices.org/mhidd-national-research-consortium to review the annual report.

Beat It: US Based Pilot Evaluation of the Behavioral Activation Intervention, Beat It, for Young Adults with ID.
Pls: Dave Buck, PhD, Chattanooga Autism Center, TN; Roberto Blanco, MD, UNC School of Medicine, NC

Positive Mental Health and Autism Spectrum Disorders.
Pl: Luke Kalb, PhD, Kennedy Krieger Institute, Johns Hopkins University, MD

Using the Parent-Report Anxiety Scale to examine symptoms of anxiety for children with IDD enrolled in START.
Pl: Jennifer McLaren, MD, Assistant Professor of Psychiatry and The Dartmouth Institute, Dartmouth Hitchcock Medical Center, Medical Director, New Hampshire Bureau of Developmental Services

Examining the Mental Health of Autistic College Adults.
Pl: Brian Freedman, PhD, Senior Associate Director, University of Delaware Center for Disability Studies, DE

Examining cognitive accessibility and clinical applications of the VIA Character Strengths Survey.
Pl: Ariel Schwartz, Postdoctoral Fellow, Boston University

Pl: Ty Aller, PhD, Utah State University

Looking ahead: The 2021 National Research Consortium Conference will be held on October 14 at the Kennedy Krieger Institute in Baltimore, Maryland. The conference will focus on participatory research and include training developed by the research team for the PCORI project titled Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research Project.

Systems Analyses

Rhode Island

In 2020, CSS collaborated with the State of Rhode Island’s Department of Behavioral Health Care, Developmental Disabilities and Hospitals (BHDDH) to conduct an analysis on mental health and crisis services for people who have ID/DD in the state. This comprehensive study combined data from an online community survey, targeted focus groups, and telephone interviews with service users. The goal was to determine where the service system is working well for individuals with IDD and mental health needs, what services could be improved, and where there are gaps in existing services. A report was presented to RI stakeholders in March, 2020 and recommended improved systems linkages, access to training and best practice methods, trained case managers/service coordinators to help individuals and families navigate the system, cross systems crisis prevention and intervention planning, trained and reasonably compensated direct support professionals, and improved access to qualified outpatient, inpatient, and crisis mental health services.

Looking ahead: CSS is currently in the process of conducting two system analyses. The Tennessee analysis focuses on TN crisis respite programs to determine the training needs of these programs as part of the statewide launch of TN START/ AST clinical teams. The second analysis in being conducted in collaboration with The Arc of Texas as part of their Whole Person Project, designed to eliminate barriers to care for Texans with intellectual and developmental disabilities (IDD) who need mental health supports. An analysis of current training and professional development practices in Texas to determine enhancement opportunities for professionals in the field of IDD and/or mental health. Over the course of the five year grant, CSS will provide professional development opportunities and technical support in our work with The Arc of Texas.
Recent Peer-Reviewed Publications

Invited & Peer Reviewed Presentations
Center for START Services Virtual Orientation Series. (December 2020)
- Harvey, K., Hinton, J.E. Understanding Trauma and MH/IDD
- Hinton, J.E., LaForce, A. Trauma-Informed Care Approaches
- Habib, D., Weigle, K.L. Now We Have Hope: The Strength of the START Community (START Film)
Center for START Services Virtual Orientation Series. (October 2020)
- Hingsburger, D., Hinton, J.E. A Talk on Sexual Identity
- Caoili, A., Hinton, J.E., McLaren, J. START Practices to Promote Inclusion
Center for START Services Virtual Orientation Series (August 2020)
- Beasley, J.B., Tomasulo, D. Positive Psychology & START Foundations
- Beasley, J.B., O’Neal, D. Crisis Assessment and Prevention
START National Training Institute, Washington, DC. (May, 2019).
- Weigle, K.L., Habib, D., Cyrus-Savary, S., Brent, D., Casa Bibiana, C., Gunter, D., Oosting, S., & Utley, B. Premiere of the START Film and Panel Discussion