Our Research Panel

- Luke Kalb, PhD, Chair, National Research Consortium in MH-IDD; Assistant Professor, Kennedy Krieger Institute; Johns Hopkins Bloomberg School of Public Health
- Andrea Clark, LCSW, Director of Research and Quality Assurance, Center for START Services, IOD/UNH; Operations Manager, National Research Consortium in MH-IDD
- Jessica Kramer, PhD, OTR/L, Associate Professor, Dept of OT, College of Public Health and Health Professions, University of Florida
- Destiny Watkins, DeTera Wellness Advocate; PCORI Research Leadership Team
- Micah Peace, Louisville’s Center for Accessible Living, PCORI Research Leadership Team
- Tawara Goode, MA, Assistant Professor, Dept of Pediatrics; Director, Georgetown University Center for Child and Human Development; NCC (GUCCHD); Director, Center for Cultural National Center for Cultural Competence (NCCC), GU
- Joan B. Beasley, PhD, Research Associate Professor, Director of the Center for START Services, University of New Hampshire, Institute on Disability/UCED; PI National Research Consortium in MH-IDD

Purpose

- To accelerate the development and implementation of evidenced-based mental health diagnostic, treatment and supportive practices for those with MH-IDD.
- To facilitate partnerships between self-advocates, families, researchers, and nonprofit agencies to guide the research agenda and interpret the findings.
Organizational Structure

Leadership

Board & Partners

https://www.centerforstartservices.org/mhidd-membership-partners

2019 Annual Meeting
at the Kennedy Krieger Institute

Going Forward

• Just accepted our first round of applications for funding

• The Board will be scoring the applications and making decision about funding!

• Stay Tuned
Crisis Contacts in START

Luther Kalb, PhD
Chair, National Consortium
Assistant Professor
Kennedy Krieger Institute
Johns Hopkins Bloomberg School of Public Health

Institute on Disability/UCED
University of New Hampshire

Goal

• To characterize the timing, nature, type, and predictors of crisis contacts in START

• N=1188 children and youth from 8 states

Timing

• Overall, 31% experienced a crisis
• Increase in crises 90 days after enrollment
• Steep drop off thereafter
• Half of crises happened after 6 months
• 25% occurred after 9 months
• Very few after 1 year.
START Model Guiding Principles

- Positive Psychology & Strengths Based Practice
- Person & Family-Centered
- Cultural and Linguistic Competence
- Trauma-Informed
- Bio-Psycho-Social
- Wellness Based

Evaluation and Evidence Informed Decision Making

- START Information Reporting System
- Clinical assessment
- Program evaluation
- Applied research in IDD/MH

Current START Programs & Projects
Initial Response

- Initiated a COVID-19 Resources Webpage
- Modified service delivery using telehealth methods
  - Virtual Outreach
  - Virtual Therapeutic Coaching
  - Assessments
- Revised data collection methods to gather important information re: efficacy of virtual services
- Held focus groups and network meetings-START directors, clinical directors, team leads, coaches, counselors, etc.
- Developed a COVID-19 Family Interview Tool to gather necessary information and input from families

START service users are resilient
- Families have grit and persevere
- START teams are dedicated
- Relationships matter- Network and community partnerships have been key

A robust data and evaluation infrastructure allowed us to mobilize quickly.

N=2660

<table>
<thead>
<tr>
<th>Virtual Supports</th>
<th>Number of people</th>
<th>% of Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach</td>
<td>2340</td>
<td>88%</td>
</tr>
<tr>
<td>Therapeutic coaching</td>
<td>329</td>
<td>12%</td>
</tr>
<tr>
<td>Reactivated</td>
<td>32</td>
<td>1%</td>
</tr>
</tbody>
</table>

• Total number of people served across START Programs: 2660
• Total number of people who received virtual outreach: 2340 (88%)
• Total number of people receiving virtual therapeutic coaching: 329 (12%)
• Some people who were recently identified as “stable” were re-activated due to stressors and circumstances associated with COVID-19
Crisis Response

<table>
<thead>
<tr>
<th>Crisis contact</th>
<th>Number of People (Percent of total calls)</th>
<th>% of Total START Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total contacts</td>
<td>367</td>
<td>14.5%</td>
</tr>
<tr>
<td>Maintained</td>
<td>293 (76%)</td>
<td>11%</td>
</tr>
<tr>
<td>ER/home</td>
<td>54 (14%)</td>
<td>2%</td>
</tr>
<tr>
<td>MH inpatient</td>
<td>19 (5%)</td>
<td>.007%</td>
</tr>
<tr>
<td>ER/HSN</td>
<td>14 (4%)</td>
<td>.005%</td>
</tr>
<tr>
<td>MH Stabilization</td>
<td>4 (.5%)</td>
<td>.001%</td>
</tr>
<tr>
<td>Med admit</td>
<td>3 (.5%)</td>
<td>.001%</td>
</tr>
</tbody>
</table>

COVID-19 Family Interviews

- START service users residing with family: 1600
- Completed interviews as of 5/1/2020: 500
- Access to internet
- Changes in caregiving needs in the home
- Change in financial situation/employment, school, etc.
- Changes/disruption in services

"We do not have a smart phone or internet service."
"My biggest worry is me getting sick. I don't have a contingency plan."
"We have to use the cell phone outside to connect to school sessions."

"COVID-19 is not the only crisis that is occurring."

"Sometimes I think how crazy it is to have 3 children with Autism all stuck at home"
"We choose not to have services at this time. We prefer to keep safe without bringing anyone in even though its hard not have support people around."
"Crises are beginning to increase."
"Art supplies from START team were helpful."
"Outreach has been helpful. She has settled down now and is in good spirits."
Implications

• Increase in frequency and decrease in duration of planned contacts can have an impact on service users during COVID-19, but we need to study this more.
• Crises are increasing as stay at home orders are extended.
• Recidivism is also on the rise—people are calling for crisis supports more often.
• We need to be prepared as a network and as a MH community to respond to increasing emergent and acute needs of people with IDD.

START Crisis Task Force has been developed to continue to respond to the needs of the START community and beyond: Mobile crisis response, therapeutic supports, transition planning.

Next Steps

• We need to continue to evaluate the impact of COVID-19 and consider a wide array of factors:
  - Race, ethnicity, living situation, socioeconomic status, diagnoses, medical concerns, service disruption
• START service delivery will look different from this point forward:
  - Intake/information gathering: Access to technology, high speed internet
  - Plain language forms and tools
  - Preference for in-person or virtual (combination of both)
• Virtual methods for connection across the network will have a lasting impact on how we all operate:
  - Crisis Task Force is ongoing
  - Virtual therapeutic groups—Sharing resources around the country
Funding Acknowledgments
This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EA #15364)

Leadership Team (In order of appearance!)

Jessica Kramer, University of Florida
Tawara D. Goode, National Center for Cultural Competence, Georgetown University
Micah Peace, Louisville’s Center for Accessible Living
Destiny Watkins, DoTerra Wellness Advocate
Joan B. Beasley, UNH IOD & Center for START Services

What is Truth and Reconciliation?

- Truth and Reconciliation is an important concept in societies that have experienced deep inequities and injustices and where the communal trauma of these injustices has seldom been acknowledged.
Truth and Reconciliation is a process that has been used in international and domestic conflicts across the world and has been recently applied to human service systems in the United States, including the field of medicine.

U.S. Examples

In June 2008, a historic apology was issued within this nation’s own medical community. The President of the American Medical Association apologized to the National Medical Association for past wrongs and discrimination against African American physicians and communities. “I unequivocally apologize for our past behavior. We pledge to do everything in our power to right the wrongs that were done by our organization to African American physicians and their families and their patients. We’ve expressed our heartfelt contrition, and I hope that we can continue down a path toward stronger and stronger collaboration and partnership.”

President of the American Medical Association (2008)

In May 2011, former Governor LePage joined Native American officials from Maine’s five tribes in signing a Declaration of Intent to create a process to shed light on the terrible injustices of the past, promote healing, and improve public policy. This was the first truth and reconciliation process in U.S. history to be developed by both sides in partnership.

Applying a Truth and Reconciliation Model to Research

The Georgetown University National Center for Cultural Competence (NCCC) conducted a truth and reconciliation project entitled, The Legacy of Research in Culturally Diverse Communities: Acknowledging our Past... Shaping our Future. It was designed to answer the question:

Can barriers to participation in research by racial and ethnic groups (other than non-Hispanic White) be reduced by “truth and reconciliation” community forums?

To implement the project, the NCCC adapted a truth and reconciliation model comprised of four phases that engaged both those communities that were historical victims of exploitation and those communities that historically committed the exploitation – intentionally or unintentionally.

The model involves the following four phases:
- Truth Telling
- Acknowledging
- Restoring
- Collaborating
Applying a Truth and Reconciliation Model to Research

1. Truth Telling – an authentic open exchange regarding the damage of past research practices

2. Acknowledging – affirming and learning from the past and embracing new possibilities for future research

3. Restoring – addressing the problems of the past and ensuring the safe conduct of research based on established policy and practice.

4. Collaborating – acknowledging the inherent power of communities to recognize their own problems, including the health of their members, and collaborating with these communities in the conduct of research which values and respects community solutions for community problems.
Applying a Truth and Reconciliation Model to IDD-MH Research

Truth and Reconciliation has significant implications and is highly applicable to the IDD-MH due to the history of exploitation, harms, and exclusion. We adapted the NCCC’s original model for our PCORI project. We ask you to join us as we take this journey to reconcile the past and change the future.

Why does Truth & Reconciliation matter?

- Micah Peace
- Destiny Watkins
Why does Truth & Reconciliation matter?

- Researchers make mistakes and need to apologize and learn from their mistakes.
- Learn to work with someone with a disability.

Why is it important to engage people with IDD-MH in research?

- Micah Peace
- Destiny Watkins
Why is it important to engage people with IDD-MH in research?

- People with IDD-MH know what other people with IDD-MH may want or need.
- They can make sure research is accessible to other people with IDD-MH.

How Does This Fit the Mission of START?

- Our mission is to know better in order to do better
- We are dedicated to humanism and best practices
- False beliefs cannot change, and inferior practices cannot improve, without inclusion of people with lived experiences
- We must face our history and ourselves in this process
- This project allows us to move forward with our goal to develop research opportunities that make a difference.