Membership Partners Presentation
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Sponsoring members invested in research and development toward best practices and policy change to promote effective outcomes. The research agenda is heavily influenced by their priorities.

George Contos, YAI    Connie Horton, Hogg Foundation
John Dickerson, Quillo    Susan Klick, Family Member
Melanie Hecker, Self-Advocate    Dan Tomasulo, Columbia U
Tawara Goode, Georgetown U
Joni Beasley, CSS
Connie Horton, Hogg Foundation

1. How/Why did you get involved in the MH/IDD field?
   
   a. Started in direct care at age 13 – recreation program for kids with disabilities in Northern Virginia

   b. Daughter born with autism and ID in 1990 – she is now 28 years old

   c. Worked at the Univ. of Texas UCED for ten years as director of policy

   d. Now at the Hogg Foundation for Mental Health at the University of Texas at Austin working to improve access to mental health services for people with ID

2. Why did you decide to be part of this consortium?

   a. There continues to be wide gaps between the need for mental health services for individuals with ID, and access to those services.

   b. The continued focus on managing behaviors without addressing the impact of trauma and the potential for mental health conditions prevents many individuals with ID from attaining recovery from their mental health condition.
3. What do you hope to see come from it?

a. Increased awareness of the need to address the mental health and wellness of individuals with IDD

b. Improved access to mental health services for individuals with IDD, and

c. An evidence-base to help support needed systems policy changes.
John Dickerson, Quillo

1. How/Why did you get involved in the MH/IDD field?
   a. I became involved in the field in 1973 and very shortly was introduced to people at Redfield State Hospital who were given many labels. I was with The Arc then and saw how quickly aversive techniques and restraints were the order of the day. Luckily in my first six months I had the chance to spend three days with Burton Blatt and that launched my career in the right direction.

2. Why did you decide to be part of this consortium?
   b. I am a huge fan of START and DR Joni Beasley. When she asked I jumped at the chance to be part of this effort.

3. What do you hope to see come from it?
   c. I look forward to learning from others and building a greater consensus on expanding the impact of the directions being developed to reach more people in need of a different approach.
Dan Tomasulo, PhD, TEP, MFA, MAPP
Core Faculty Spirit Mind Body Institute
Columbia University, Teachers College
Master of Applied Positive Psychology Program
University of Pennsylvania
Director NY Certificate in Applied Positive Psychology
- Installation of Hope
- Universality
- Imparting Information
- Belonging/Cohesiveness
- Catharsis
- Support
- Existential Factors
- Interpersonal Learning
- Altruism
- Simulation of primary family
- Corrective emotional experience
- Development of Social Skills
- Feedback & Confrontation
- Group as a microcosm
1. How/Why did you get involved in the MH/IDD field?

Although YAI was founded in 1957, the organization continues to operate according to the same principles – that people with intellectual and developmental disabilities (I/DD) should have an opportunity for the same level of growth, learning, and independence as the neurotypical population.

In 2019, our organization provides a comprehensive range of services that support that growth. Because people with I/DD often experience greater discrimination and difficulty accessing services, YAI has always sought opportunities to link our day-to-day residential, day, healthcare, and training services to mental health care.
2. Why did you decide to be part of this consortium?

YAI decided to be a part of this consortium as a result of our involvement with START program and partnership with the Center for START Services. We are happy to collaborate with the Center on this initiative and to demonstrate our ongoing commitment to supporting people with I/DD and co-occurring behavioral and mental health needs.

YAI’s mission of living, loving and working is perfectly aligned with the START’s program’s strengths-based approach to providing people with I/DD mental health services that are at once local, person-centered, cost-effective, and evidence-informed for the greatest quality of life.
3. What do you hope to see come from it?

While focus on mental health at the population level has increased over the past several years, health systems continue to struggle to provide adequate care for vulnerable people, particularly when facing mental health crises.

As YAI becomes more involved the consortium, we hope to see greater involvement from peer organizations collaborating on the implementation of the START model.

We are also eager to benefit from additional research that illuminates the efficacy of specific treatment modalities on behalf of people with I/DD.
Susan Klick, Family Member
The journey that began 45 years ago

- Colicky
- Constantly cried
- Didn’t sleep (2 hours max)
- Delayed speech
- Frequent respiratory infections
- Numerous antibiotics
- Overly energetic toddler
- Far-away look

“He’ll outgrow this developmental delay.”
The journey, and its challenges, continues

- Special school placement
- Challenge the administration
- Irregular learning retention
- Other challenges:
  - Seizures
  - CAT scans
  - Allergy testing
  - Special diets
  - Genetic testing
  - Holistic health plans

Unfortunately, no miracle solution was found…
The journey that reached its breaking point

Depression

Psychoses

Neuroleptic Malignant Syndrome
The journey that is ever-changing

- DDS Advocate & State Administrators
  - No longer working
- UMASS Neuropsych Unit
  - Closed due to lack of funding
- State funded community provider
  - Pressured to reduce services
- His story has been forgotten
  - Replaced with broad-brush approach

One size does NOT fit all.
The journey that is my lifetime mission

- Early immune system intervention
  - Less use of antibiotics at a young age
  - Explore integrated, holistic, homeopathic medicine to compliment
- Diet of healthy organic foods
- Therapy tailored to the individual
- Recognizing medication that is not improving the individual’s condition
  - Use slow reduction schedule
- Proactively reduce abuse, neglect, and incident counts
- Programs to improve every individual’s current status
  - Provide programs, services, jobs to improve the lives of the individuals
- Record, measure, and track all results
- Importance of data & analytics to track specific progress
- Encourage, support & advocate for these individuals
Melanie Hecker, Self Advocate

My Beginning
- Knew I was “different” from earliest memory; diagnosed with Asperger’s (now autism) at age six and Bipolar Disorder at age thirteen

My Challenges
- Relations with my peers were always difficult; finding schools and schooling itself was a challenge. Obtaining state services was extremely hard.
- Seven inpatient psychiatric stays; a lot of psychiatric medication
- I always needed to develop coping strategies

My persistence
- At the age of 15, I began speaking publicly about my disabilities
- In 2013, I began working at YOUTH POWER! In 2016, I received my A.S. in Human Services and began my Public Policy BA at UAlbany
- In 2018, I was accepted to the accelerated Combined BA/MPA
- In May 2019, I graduated Magna Cum laude with my BA and was a commencement speaker
- I received the ILCHV Beacon Leadership Award that same week
Melanie Hecker, Self Advocate

Why am I participating
• Dual Diagnosis of MH/DD is extremely common
• Dual Diagnosis is under-addressed in both the policy and clinical senses
• Many dually diagnosed people cannot access supports for either disability
• “Nothing About Us Without US”
• Projects like this need the people who are affected to be actively involved

What I hope to get out of it
• I hope a better understanding of dual diagnosis will lead to better outcomes
• I hope policymakers will take notice of our effort and try to bring about real change
• I hope clinicians will be more willing to accept dually diagnosed patients
• I hope people like me can finally get what we need and deserve
Tawara Goode, Georgetown

1. How/Why did you get involved in the MH/IDD field?

a) As a faculty member of the Georgetown University Center for Excellence in Developmental Disabilities, I have been in the field of intellectual and developmental disabilities for many, many years.

b) My other hats at the Georgetown University Center for Child and Human Development (GUCCHD) also provided an opportunity for me to work in child and adolescent mental health, through a long-term SAMHSA-funded technical assistance center at Georgetown.

c) Where these two fields intersect is my early work on GUCEDD projects specifically devoted to District of Columbia adult population with IDD and mental health needs.

d) For the past three years or so, I have been collaborating with the Center for START Services to intentionally integrate culturally and linguistically competent principles, structures, and practices into the work of the START national network.
2. Why did you decide to be part of this consortium?

   a) Joni made me an offer I could not refuse - *literally*.

   b) I am interested in the promise of expanding the body of literature on IDD-MH in several salient ways that are important to me.

   c) There is a dearth of research, both areas of inquiry and methods, that is committed to the meaningful participation of culturally diverse individuals with IDD-MH, their families, and the communities in which they live.

   d) Influencing researchers to attend to the unique circumstances of individuals and their families who experience intersectionality because of their disabilities, race, ethnicity, languages spoken, and other cultural variables.

   e) Increase the capacity to integrate culturally and linguistically competent approaches in the conduct of research.
3. What do you hope to see come from it?

a) A positive movement in:

b) Cultural and linguistic competence is necessary to mitigate long-standing research priorities and methodologies used in institutions of higher education that have resulted in underrepresentation of diverse racial and ethnic groups relative to their proportion of the population.

c) There is a growing movement by federal agencies, including the National Institutes of Health, to address the underrepresentation of diverse racial and ethnic groups in large scale studies.

d) Cultural and linguistic competence is an essential approach to address the history of mistrust of research among culturally diverse populations and within many communities of color.

e) There is a need to document cultural variations in response to treatment and other health and mental health interventions among diverse populations.

f) Research will prove more valuable if the culturally diverse populations that are studied have an investment and are active participants in all aspects and phases of the research process.
Joni Beasley, CSS

1. How/Why did you get involved in the MH/IDD field?
   a) I worked closely with several leaders in the field in the early 1980’s and I have been doing this ever since. As a mental health practitioner and policy researcher, I have seen that so much more can be done to help people with slight shifts and increased awareness.

2. Why did you decide to be part of this consortium?
   b) I think that I developed this consortium concept because for years we have learned that synergy, working together fosters improved abilities and greater resources.

3. What do you hope to see come from it?
   c) I hope that we can influence research priorities and resources dedicated to this population.