Purpose, Structure, and Goals

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www.centerforstartservices.org
Outline

• Background
  o Why we are developing this consortium

• Organizational Structure
  o Who is involved

• Goals and Activities
  o What we are aiming to do
Background

• Individuals with Intellectual and Developmental Disabilities (IDD) have significant mental and physical health needs

• Compared to the general population, those with IDD are:
  
  o 2-3 times more likely to have a mental health condition
  o 5 times more likely to have diabetes
  o 2 times more likely to have cardiovascular disease
  o 3+ times more likely to be hospitalized/visit the ED

  o The lifespan for those with IDD is 20 years shorter
ARC

“all people with intellectual and/or developmental disabilities should have timely access to high quality, comprehensive, accessible, affordable, appropriate healthcare that meets their individual needs, maximizes health, well-being, and function, and increases independence and community participation.”
An Important Cause

• Lack of Research and Funding
  
  o Individuals with IDD have been historically treated as an exclusion criteria
  
  o Limited research dollars have supported MH/IDD research
Purpose

• To accelerate the development and implementation of evidenced-based mental health diagnostic, treatment and supportive practices for those with IDD.

• To facilitate partnerships between self-advocates, families, researchers, and nonprofit agencies to guide the research agenda and interpret the findings.
Organizational Structure

Leadership

Responsible for Organizing and Managing Consortium Activities

Joan B. Beasley, PhD
Consortium Director

Luke Kalb, PhD
Chair

Andrea Caoili, LCSW
Director of Operations
Organizational Structure

Membership Partners

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

Towara Goode, Georgetown U

Joni Beasley, CSS
Organizational Structure

Researchers and Scholars
Contributes to implementing the scholarly activities

You!
Background

National Advisors

Policy and practice leaders

Yona Lunsky, PhD  
*University of Toronto*

Angela Hassiotis, MD  
*UCL, London, UK*

Brian Hepburn, MD  
*National Association of State Mental Health Program Directors*
Goals and Activities

• To engage in the activities identified in the membership survey.

• To use the Consortium as a formal vehicle of collaboration.
Goals and Activities

• Conduct High-Quality, Impactful, Applied Research
  o Meta Analyses, Scoping Reviews
  o Services Research
  o Intervention Studies

• Secure larger grant funding for collaboration
  o Federal: NICHD, NIMH, SAMSHA
  o Private Foundations