



RECONCILING THE PAST AND **CHANGING THE FUTURE**

Engaging Young Adults with IDD–MH and Researchers in Comparative Effectiveness Research

PROBLEM STATEMENT

It is estimated that 40 to 60% of people with intellectual and developmental disabilities (IDD) experience a co-occurring mental illness, a prevalence rate that nears seven times greater than those without IDD. Despite the prevalence of mental health needs among people with IDD, little is known about approaches that can optimize their lifelong mental health and well-being. The paucity of research and evidence-based practices has led to potential over reliance on seclusion, restraint, and medication as treatments of first choice. Repeated and extended hospitalizations/institutionalization threaten the human rights and autonomy of people with IDD, exacerbate mental and physical health problems, reduce capacity to be employed and engage in leisure/exercise, and live within the communities of their choice. There is a critical need to provide timely, accessible, and effective mental health interventions to young adults with IDD to ensure their transition to adulthood is successful from the start.

There is little to no research comparing the effectiveness of mental health interventions for individuals with IDD. People with IDD are among the largest recipients of psychopharmacologic mental health treatment, although little evidence is available to support these practices. There is a critical need to expand research, in partnership with young adults with IDD who have mental health needs and service experiences (IDD-MH) and their families, to provide evidence for interventions and outcomes valued by this population. Research has historically excluded people with IDD-MH across the age span, and as a consequence, researchers continue to be informed by erroneous assumptions regarding the abilities, interests, and needs of this population. This is further compounded by intersectionality. Individuals with IDD-MH face greater degrees of exclusion due to their membership in multiple social groups that are subjected to marginalization and discrimination because of overlapping racial, ethnic, gender, and disability identities. Increasing researcher knowledge of the harms associated with exclusion and forging a new path to rectify the past is an essential step toward reconciliation.

Project Approach

This project is a collaboration of the [University of Florida, Georgetown University National Center for Cultural Competence \(NCCC\)](#), and the [Center for START Services \(CSS\) at the University of New Hampshire, Institute on Disability](#). Both the NCCC and CSS are programs are under the auspices or associated with their state's University Centers for Excellence in Developmental Disabilities (UCEDD). Adapted from a Georgetown University NCCC model, this is the first project explicitly designed to provide an innovative process for reconciliation and meaningful involvement of young adults with IDD-MH and their families in comparative effectiveness research (CER). The project is grounded in the principles and practices of community engaged research, cultural and linguistic competence, universal design for learning, and positive psychology. These principles and practices are exemplified by stakeholder engagement at all levels of the project including two young adults with IDD-MH who are members of the leadership team, a national advisory committee comprised of key stakeholders, CSS staff, START network staff, and the [National Research Consortium on Mental Health in Intellectual and Developmental Disabilities](#). The project will use Truth &

Reconciliation Forums 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 CER.

Goal and Aims

The goal of this project is to build capacity for researchers and young adults with IDD-MH and families to engage in CER.

Aim 1: In partnership with stakeholders, adapt extant Truth & Reconciliation Forum protocol and materials for young adults with IDD-MH and families and develop Transforming Research Forum protocol and materials for researchers.

- Objectives:
- 1.a. Provide a process for young adults with IDD-MH and families to:
 - Begin to reconcile experiences of marginalization and exclusion in research and practice.
 - Acquire knowledge and skills to partner effectively in research.
 - Create partnerships and dissemination approaches that are inclusive and culturally and linguistically appropriate for this population.
 - 1.b. Facilitate researcher knowledge of:
 - The value of partnering with young adults with IDD-MH and families in CER.
 - Culturally and linguistically appropriate approaches to engage, partner with, and disseminate information on CER to this population.

Aim 2: Implement, evaluate, and revise the forums with stakeholders.

Aim 3: Create and disseminate strategies for culturally and linguistically appropriate CER partnerships to young adults with IDD-MH, families, and researchers.

Anticipated Outcomes

At the conclusion of the project there will be increased capacity of young adults with IDD-MH, their families, and researchers to partner in CER that optimizes the health outcomes valued by this population. The project will create a number of products and publications including but not limited to materials and guides to conduct truth and reconciliation and transforming research forums that will be disseminated to the public.

Funder

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