



# RECONCILING THE PAST AND **CHANGING THE FUTURE**

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

### Why is this project important?

All people have mental health needs at some time. People with intellectual/developmental disabilities (IDD) also have mental health needs.



Mental health needs are more common in people with IDD than people without disabilities.

We don't know enough about the best way to help people with IDD who have received mental health services (IDD-MH).



Many people with IDD-MH have their mental health treated by:

- Taking strong medications.
- Taking a lot of medications.
- Going to a hospital or institution.
- Using physical restraint sometimes.



These treatments may make their mental and physical health worse, and may hurt people with IDD-MH.

We don't know enough about what people with IDD-MH need and want.

Many people with IDD-MH may not know about their rights and choices.



This makes it hard for people with IDD-MH to have independence in the community.

Young adults with IDD-MH need good mental health treatment and support.

Good treatment and support will help them become successful adults.



## What is the problem?

We need more research about people with IDD-MH.

Many people with IDD-MH receive a lot of psychiatric medications. But we do not know if these medications help people with IDD-MH.



Other treatments besides medications may work.

We need research that compares different types of treatments and supports to find out what works best.



In the past, many people with IDD-MH have been left out of research.

Some people with IDD-MH had research done to them, without their permission or understanding.

This kind of research hurt people with IDD-MH.



Today, many people with IDD-MH are still left out of research. Researchers may not have all the information they need about the abilities, interests, and needs of people with IDD-MH.



People with IDD-MH are often left out from research for many reasons. Some reasons are:

- Race or ethnicity
- Gender or gender identity
- Sexual orientation
- Age
- Problems communicating
- Disability



Sometimes people with IDD-MH are left out because of discrimination.

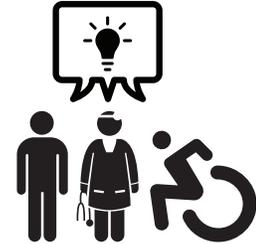
Discrimination happens when people or groups of people are treated differently from other people, in a way that is unfair or unequal.



## What can we do about the problem?

Research needs to include young adults with IDD-MH and their families.

This will help provide treatments and supports that are important to young adults with IDD-MH and their families.



People with IDD-MH and their families can help decide:

- What type of research is important to them.
- How to do the research.
- What the research means.
- What do with the information from the research.



Researchers, people with IDD-MH, and their families can all learn new ways to partner and conduct research together.

There are many people that live in the United States. They all have diverse backgrounds. This includes:

- Race or ethnicity
- Gender or gender identity
- Sexual orientation
- Age
- Disability
- Differences communicating



Young adults with IDD-MH from all backgrounds need to be included in research. This helps make sure that research includes their needs, interests, and experiences.

## Who is doing this project?

These are the people working on this project:

University of Florida



Georgetown University National Center for Cultural Competence (NCCC)



The Center for START Services (CSS) at the University of New Hampshire, Institute on Disability



Advocates with IDD and mental health challenges  
Family members

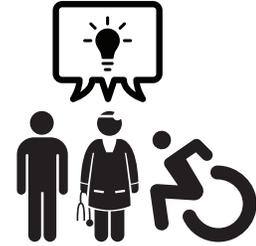


Researchers & mental health professionals



## What will happen in this project?

The goal of this project is to help people with IDD-MH, their families, and researchers learn how to do research together.



Our project will use strategies to make sure we:

- Include people with different backgrounds.
- Work together.
- Value people's unique strengths.
- Respect differences.



Georgetown University did a similar project like this. We are using this project as a guide for our project.



National Center for  
Cultural Competence  
AT GEORGETOWN UNIVERSITY



## Project Goal 1

We will conduct an activity for young adults with IDD-MH and their families.

This activity is called "Truth and Reconciliation." For our project, reconciliation means young adults with IDD-MH, families, and researchers working together to make things better and build a relationship based on trust.



The activity will help people with IDD-MH and their families:

- Learn about some of the bad things that happened during research in the past.
- Try to build trust with researchers.
- Figure out how to make research better.
- Connect people with IDD and their families to researchers.



This activity will keep in mind people from diverse backgrounds: race, ethnicity, cultures, gender and gender identities, sexual orientation, age, income levels, education, and disabilities.



## Project Goal 2

We will conduct an activity for mental health researchers. This activity is called “Transforming Research.”



This activity will help mental health researchers:

- See the benefit of doing research with young adults with IDD-MH and their families for everyone involved.
- Make sure no one feels left out of research.
- Make sure that everyone can understand and benefit from research information.



This activity will keep in mind people from diverse backgrounds: race, ethnicity, cultures, gender and gender identities, sexual orientation, age, income levels, education, and disabilities.



## Project Goal 3

We will do both activities across the United States and on the internet.

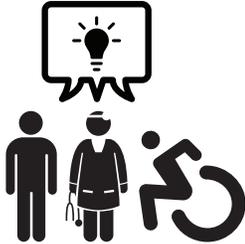


We will see if young adults with IDD-MH, their families, and researchers like the activities. If they do not like them, we will try to make them better.



## Project Goal 4

We will share what we learn with other young adults with IDD-MH, their families, and researchers.



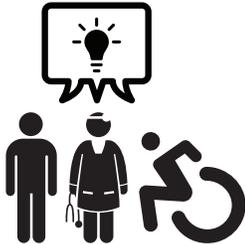
We will be sure that **everyone** can understand and benefit from what we learned.

**Everyone** means we include and share what we learned with people from diverse backgrounds: race, ethnicity, cultures, gender and gender identities, sexual orientation, age, income levels, education, and disabilities.



## What will happen after this project is over?

The goal of this project is to help people with IDD-MH, their families, and researchers learn how to do research together.



By doing research together, we hope that all young adults with IDD-MH will:

- Have better mental and physical health.
- Have more independence and choice.
- Be respected and valued.
- Be successful adults, living in their community.



**UF** College of Public Health and Health Professions  
Department of Occupational Therapy  
UNIVERSITY of FLORIDA

Jessica Kramer  
jessica.kramer@php.ufl.edu



National Center for Cultural Competence  
AT GEORGETOWN UNIVERSITY

Tawara D. Goode  
tdg2@georgetown.edu



THE CENTER FOR START SERVICES  
Institute on Disability/UCED  
University of New Hampshire

Joan B. Beasley  
Joan.Beasley@unh.edu