



RECONCILING THE PAST AND **CHANGING THE FUTURE**

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

Understanding the Impact of COVID-19 on Young Adults with IDD–MH and their Families

*An Analytical Framework and Database to Identify Service Experiences
and Outcomes Across Diverse Populations in Real Time*

Many public health crises have a disparate impact on marginalized populations including sub-groups at the intersection of race, ethnicity, and disability. It is unknown how the COVID-19 pandemic will affect young adults with intellectual and developmental disabilities who have mental health service needs and experiences (IDD-MH) and their families across the U.S. Most national databases either: (1) exclude this population, (2) collect such data but do not disaggregate by age and disability status, or (3) do not gather the granular data required to identify potential disparities across sub-groups by race, ethnicity, languages spoken, limited English proficiency, and low socioeconomic status.

This PCORI-funded project leverages the existing infrastructures of the *Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research* Project. Center for START Services (CSS) at the University of New Hampshire, Institute on Disability is collecting real-time data to document the incidence and effect of COVID-19 and mental health service use during this public health crisis. START programs provide mental health service supports in 25 regions and 13 states, including the COVID-19 hotspots of NYC, Seattle, and Northern CA. CSS operates the START Information Reporting System (SIRS), a comprehensive database with 8,000 START enrolled individuals. CSS distributed the “COVID-19 Family Survey” on 3/15/20 for START programs to collect granular quantitative and qualitative data on the effect of the crisis and to enhance START’s response. This project will provide a framework to analyze mental health service use and outcomes before and after the on-set of COVID 19. This is a unique and valuable source of information that will inform interventions and supports for this vulnerable and underserved population. The project will draw upon analytical frameworks developed by Georgetown University National Center for Cultural Competence (NCCC) that examine intersectionality and the convergence of cultural contexts. Applying similar frameworks to the SIRS dataset can identify crucial needs for future comparative effectiveness research (CER) and equip mental health systems with the information to facilitate more equitable outcomes in future public health crises.

Supplement Aim 1: Gain an in-depth understanding of the experiences of families of young adults with IDD-MH in the context of the COVID-19 crisis. CSS’s “COVID-19 Family Survey” includes an open-ended question for families to share their experiences and recommendations to service providers. The project will complete a content analysis to identify recommendations and requests.

Product/Outcome: An initial content topic list of needs and recommendations within 3 months; followed by in-depth analysis incorporating the Aim 2 analytical framework to create a report informed by families’ perspectives to identify implications for mental health research.

Supplement Aim 2: Develop an analytical framework that considers the convergence of cultural contexts and intersectionality on the COVID-19 related experiences and outcomes of young adults with IDD-MH and their families. The project will build upon Georgetown University NCCC's existing frameworks and its team's expertise to develop an analytical framework to guide COVID-19 research.

Product/Outcome: The analytical framework will be broadly disseminated so that all researchers examining the impact of COVID-19 on mental health will consider the convergence of cultural contexts and intersectionality on observed outcomes.

Supplement Aim 3: Partner with National Research Consortium on Mental Health in IDD (NRC) researchers and young adults with IDD-MH to apply the analytical framework to data collected about COVID-19 and other data variables in the SIRS national database. The project will develop a workgroup during the October 2020 NRC conference and conduct stakeholder learning forums to integrate the convergence of cultural contexts and intersectionality into research questions about the impact of COVID-19 on young adults with IDD-MH and their families using this database.

Product/Outcome: Initial findings, database, and framework will be presented to the NRC workgroup at April 2021 START National Training Institute.

Impact on Primary Project

This proposed supplemental work aligns with the goal of *Reconciling the Past & Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research* to increase the capacity of young adults with IDD-MH, their families, and IDD-MH researchers to partner in CER.

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