

Teens with disabilities are 5 times more likely to suffer from mental, emotional and behavioral health disorders

January 5 2022, by Darcel Rockett



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The pandemic has revealed some truths: A lack of mental health providers to sufficiently meet the needs of those in crisis (including

providers of color); and the stress that COVID-19 has introduced is being felt by all ages, with mental health coping strategies being constructed to help. Another truth: Young people with disabilities report poorer mental health compared with peers without disabilities.

According to University of Illinois at Chicago researchers, teens with disabilities are up to five times more likely to suffer from mental, emotional and behavioral health disorders than adolescents without disabilities.

Kristin Berg, UIC associate professor of disability and human development at the college of applied [health sciences](#), is tackling the latter issue as co-principal investigator of the Behavioral Health Stratified Treatment (BEST project)—a new \$7 million, five-year study (funded by the Patient-Centered Outcomes Research Institute) that will assess the integration of [mental health](#) services as part of state care coordination services instead of relying on referrals to mental health services.

"A lot of times PT ([physical therapy](#)), OT ([occupational therapy](#)) and speech therapy services are prioritized," Berg said. "As a country, we haven't prioritized mental health care in the sense of affordable, easily accessible health care. For people with [disabilities](#), that has been thousands (of) times more complex given access barriers and also the lack of providers in the [mental health care](#) world who are trained to deal with individuals with intellectual disabilities and autism."

As a person with a disability, Berg said a variety of factors come into play when a family attempts to get care for depression/anxiety for a child with autism—from providers who say they "don't treat intellectual disability" to finding a provider who knows about particular disability issues to finding a provider with an accessible venue. Berg added that a lot of times when a person with a disability goes in for treatment, symptoms of depression or anxiety are blamed on the disability, when

that's not always the case. Another challenge: Recognizing that individuals with disability are more likely to experience trauma.

"In my own research, clinically or anecdotally, I heard many cases of individuals with disabilities being abused and neglected," Berg said.

"When people with disabilities come into the office, there is this medical model focus on their disability. They're just addressing those symptoms of that medical condition. A lot of times behavioral health feels like it's in this other silo. Because of the siloing in training and in the profession, a lot of primary care physicians or specialists aren't trained in behavioral health, and the behavioral health workforce, they're not trained in intellectual and developmental disability. That's another factor that we see ... these professions aren't dialoguing and people with disabilities who have co-morbid depression/anxiety are falling through the cracks."

Jennifer Hernandez agrees. As a family nurse practitioner and parent to 14-year-old Camille, aka Cami, who has autism, Hernandez said it's been a battle since her diagnosis at 17 months with insurance, schooling and IEPs, and resources.

"You have a patient who has chest pain, they're on that table within 24 hours. You have a child who's having suicidal ideation? You go to the ER, you wait hours to be assessed," she said. "This is how we're treating our children in this country. It's unbelievable and shocking, and it's sad. The emotional trauma that a family already goes through and then you put this on the top?"

"We don't currently have a system where we can be like, 'Oh, a person with developmental disability and/or autism needs mental health support? Let's give them this therapy,'" said Nahime Aguirre Mtanous, a 2021-22 trainee of the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program, which provides graduate level training designed to improve the health and well-being of individuals

with disabilities. "We don't have a therapy that can best support them."

Beginning in fall 2022, UIC researchers plan to enroll and follow 780 teens (ages 13 to 20, from urban and rural settings) with intellectual and developmental disabilities and their families for 24 months to gather their health care system experiences. During the study, researchers will track how teens feel and their health behaviors by asking questions about anxiety and depression, health, health habits, functioning, ability to manage health care and self-efficacy.

The team also will track how satisfied teens, parents and health care providers are with the care coordination experience. All participants will receive care coordination from Illinois' Maternal and Child Health Services agency, but half of the participants will also receive the CHECK behavioral health component. CHECK provides community health workers and behavioral health coordinators to assist and support Medicaid recipients by intervening preventively and enhancing the referral process in physical, behavioral, and social health realms.

Berg's hope with the study: Early identification and treatment of depression/anxiety through a public health entry point of service to improve health and vocational trajectories across the life span for youth with intellectual and developmental disabilities.

"It's in everybody's best interest to intervene early and prevent the crises we're seeing now where kids are being hospitalized, going into residential settings, they're in the hospital for days with these mental health crises, which is far more expensive than if we get in there early and provide effective, brief cognitive behavioral therapy services," Berg said. "We want to eliminate all those additional steps for families that are already stressed out and dealing with a lot of stuff."

Integrating people with disabilities more generally into psychiatric and

psychological therapy services, adapting commonly used interventions like cognitive behavioral therapy and curriculum to be accessible for people with different types of disabilities is on the agenda for Berg's team of researchers, replete with disability stakeholders and investigators who have disabilities. Focus groups will advise on language, activities, visual aids and strategies on how it's implemented.

"By optimizing function and participation, every one of our systems becomes better—elderly care, care for young families," Dr. Michael Msall, professor of pediatrics at the University of Chicago, said.

"The results of this study will create new knowledge on which care coordination models result in better mental health and transition outcomes, as well as which model is preferred by youth with disabilities and their families," said the study's principal investigator Dr. Benjamin Van Voorhees, UIC professor and head of pediatrics at the College of Medicine. "Such knowledge can lead to systematic changes in how depression and anxiety are identified and treated in this population, potentially reducing existent barriers to access to behavioral [health](#) care that disproportionately impact racial and ethnic minority youth with disabilities."

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Citation: Teens with disabilities are 5 times more likely to suffer from mental, emotional and behavioral health disorders (2022, January 5) retrieved 6 May 2024 from <https://medicalxpress.com/news/2022-01-teens-disabilities-mental-emotional-behavioral.html>

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