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Tests will track improved thinking in people with fragile X, down syndromes

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Leading researchers, funded through a new, five-year, $3.2 million grant from the National Institutes of Health (NIH), are collaborating to develop and evaluate tests designed to measure and track changes in the cognitive functioning of people who typically are difficult to assess accurately: those with an intellectual disability, formerly termed mental retardation.

"The lack of good measures to document improvement in thinking that are appropriate, valid, and measure change in children and young adults with intellectual disabilities is a critical problem that is one of the largest barriers to development of new treatments to modify the underlying disease in developmental disabilities,"—said Elizabeth Berry-Kravis, professor of biochemistry, neurological sciences, and pediatrics at Rush University Medical Center. Berry-Kravis is co-Investigator of the study and site principal investigator at Rush.

"This study will help us to evaluate new, investigational treatments for people with intellectual disability," said Berry-Kravis.

The tests will eventually be used to ascertain the effectiveness of medications and other treatments, specifically for people with fragile X and Down syndromes and other intellectual disabilities. Fragile X and Down syndromes are among the leading causes of intellectual disability in the United States and around the world. Fragile X syndrome also is the leading single-gene cause of autism spectrum disorder.

"Most currently available standardized tests have been developed mainly for the general population and are not well-suited for people with intellectual disabilities," said David Hessl, principal investigator and professor in the Department of Psychiatry and Behavioral Sciences at the MIND Institute. "They just weren't designed for people with the level of functioning we typically see in fragile X and Down syndromes. What we will be working to do is modify and then validate the NIH Toolbox Cognition Battery, so that it works well for individuals with intellectual disability."

The NIH Toolbox is a multidimensional set of brief measures assessing cognitive, emotional, motor and sensory function from ages 3 to 85, meeting the need for a standard set of measures that can be used as a common currency across diverse study designs and settings. The cognitive test battery used in the study is a computer-based set of tests tapping processing speed, memory, attention and language.

The research will be conducted in concert with two other leading research institutions with robust programs in intellectual disabilities. In addition to the researchers at Rush and the MIND Institute investigators, investigators at two other universities are involved: Karen Riley, dean and associate professor, Morgridge College of Education, The University of Denver; Richard Gershon, associate professor, medical social sciences and preventive medicine-health, Northwestern University School of Medicine.

To evaluate the reliability, validity and sensitivity of the battery, over a five-year period Rush University Medical Center, the MIND Institute, and the University of Denver each will enroll 150 individuals with intellectual disability between the ages of 6 and 25 years with either fragile X syndrome, Down syndrome, or intellectual disability of unknown cause. The participants will undergo one round of testing and a second round four weeks later. The overall growth in the participants'

intellectual skills will be tested again after two years.

The Northwestern University team, which is responsible for the development, maintenance and training of the NIH Toolbox, will assist with making modifications to the tests to suit this unique population, maintain the data generated from the study, and participate in interpreting and disseminating the study findings.

Provided by Rush University Medical Center

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