$1.7M granted for unique communication measure of people with severe disabilities

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LAWRENCE — A team of researchers led by University of Kansas scientists Nancy Brady and Kandace Fleming, collaborating with Connie Kasari of the UCLA Center for Autism Research and Training, has been funded to continue the development of the Communications Complexity Scale (CCS). The CCS is a unique measure for researchers and clinicians to assess the communication status of children and adults with disabilities as diverse as autism spectrum disorders, Down syndrome, deaf-blindness and cerebral palsy, including those who are nonverbal or have very limited speech.

The Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD) provided $1.7 million for five years to hone the validity of the CCS with 300 older children and adults. The agency had helped fund the original study of 100 children that produced the beta version of the CCS. When the study results were published in 2012, more than 300 clinicians from around the world requested the test.

"Understanding the communication status of individuals with severe intellectual and developmental disabilities is difficult because they often communicate in ways that may not be readily recognized, even by clinicians," said Brady, who pioneered a communication assessment and intervention for children with deaf-blindness.

The CCS is based on the well-established continuum of "presymbolic" stages of communication development in typically developing children from birth, beginning with an infant crying or smiling, followed by eye gaze, gesturing and vocalizing directed at another person, to using "symbolic" communication, typically, spoken words.

Brady said that CCS has great potential for researchers conducting clinical trials because there really isn't anything else to quantify the effects of behavioral or pharmaceutical interventions on those individuals without speech.

"With current measures, an intervention could make a big difference in an individual's social communication, but that would never show up in terms of data if an individual is not talking yet. The CCS may be able to show progress much earlier," said Brady.

The KU research team will use the CCS to score existing UCLA tapes of individuals before, during and after interventions that focused on the play skills and joint attention that are early indications of communication development to see if the measure is sensitive to changes that occur or don't occur as result of intervention.
Brady says that clinicians and family members sometimes give up on people who are nonverbal making progress after early childhood. "But you never know when that development is going to kick in. It is not unusual for someone to start doing new things as an adult when they move to new living environment, for example, and find a new need to communicate."

At the same time, she said, individuals with Down syndrome can start the aging process earlier and the CCS should also be able to get at degenerative changes in communication.

"This will help clinicians describe an individual's current communication status much like the Rancho Los Amigos Scale does for people with traumatic brain injury," she said. "Then, appropriate therapies can be selected based on that level."

Brady is an assistant professor of speech, language, hearing sciences and disorders and associate research professor at the KU Life Span Institute. The KU co-director is statistician Kandace Fleming, assistant scientist at the Institute. Kasari is professor of psychological studies in education and psychiatry at UCLA.

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kunews@ku.edu | 785-864-3256 | 1450 Jayhawk Blvd., Suite 37, Lawrence, KS 66045

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Contact The University of Kansas

785-864-2700
1450 Jayhawk Blvd.
Lawrence, KS 66045
785-864-2700