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Beth Potier

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UNH Media Relations

Professor's Research On Angelman Syndrome Boosted By New Grant

Contact: [Beth Potier](#)
603-862-1566
UNH Media Relations

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Reporters and editors: Stephen Calculator can be reached directly at 603-862-3836 or stephen.calculator@cisunix.unh.edu

DURHAM, N.H. – For the past decade, UNH faculty member Stephen Calculator has worked to help children with Angelman syndrome -- a profound genetic disorder -- communicate with their parents, caregivers, teachers and peers. Now, with a grant from the Angelman Syndrome Foundation, Calculator will research the best practices for educating children with Angelman syndrome (AS), whose challenges include severe intellectual disabilities and an absence of speech. In particular, he will explore the role of communication instruction in fostering the inclusion of these students as active learners among their typical peers.

"For too many kids with Angelman syndrome who are allegedly included in regular classrooms, it's often little more than a social placement characterized by limited educational expectations and opportunities," says Calculator, noting that federal standards mandate that all children with special needs must be included in regular classrooms to the greatest extent possible. "Conversely, those children with severe disabilities (in general) who are being included effectively have been found to be receiving the necessary supports to be successful, as are their families and teachers. These students have been found to exhibit significant educational gains." Calculator's investigation will examine how this applies to one unique population, students with AS.

Angelman syndrome, named for the English physician who described it in 1965, is caused by a mutation of the 15th chromosome. It's estimated to occur in one in 10,000 live births, and it results in severe mental retardation, seizures, an absence of speech, low physical tone, and easily provoked laughter. "These kids are big walking puzzles," says Calculator, who notes the published incidence of the disorder has risen dramatically with advances in genetic testing and better identification.

A professor of communication sciences and disorders at UNH, Calculator was working on augmentative and alternative communication for people with communication disabilities when he connected with some families of children with AS at a conference more than a decade ago. Within the very connected network of AS families, he quickly became the go-to expert for communication.

Calculator developed a system of communication for children with AS, called enhanced natural gestures (ENGs). "I worked out a method by which you could utilize behaviors the kids were already demonstrating and shape them into meaningful gestures," he says. The gesture for "drink," for instance, might involve moving both hands to the mouth as if holding a cup. "Phone" might be a fist held next to the ear. Customized to each child, ENGs must be demonstrated to be understandable to two out of three people who don't know the child, says Calculator. "Otherwise we may end up teaching gestures that few people understand, limiting the number of people with whom children can interact."

With this \$31,000 grant from the Angelman Syndrome Foundation, Calculator will build on this work to improve the education of children with AS by identifying best practices for inclusion in regular education classrooms, with an emphasis on the role of communication. "Among the many factors we are examining will be the extent to which best practices rely on inclusive as opposed to segregated classrooms," he says.

Among the best practices Calculator will be evaluating:

- **Integration of therapy services into the classroom setting.** Instead of pulling the child out of the classroom for physical, occupational, or speech-language therapy, therapists would integrate this work into the child's regular activities. A visit to the cafeteria, for instance, can provide opportunities to practice making choices, and the playground provides physical therapy applications. "This is often a very foreign way of providing services. Most professionals provide discipline-specific services," Calculator says.
- **Utilizing natural supports.** "Natural supports," says Calculator, recruit people who would be expected to be involved in a situation and those whom a typical peer would most likely access in that same setting. "We might thus place much greater emphasis teaching children to interact with their peers and teachers than with a speech-language pathologist," he says.
- **Maintaining high expectations for all students.** For a child with AS or another profound disability who is included in a regular classroom, partial participation in activities is an important concept. "You enable a child to do as much of the activity they can, then provide support for the skills they don't have," Calculator says.

Calculator's study will conclude with a conference at UNH where participants in the study will develop action plans to enhance their students' inclusion, once again emphasizing the role of communication. Teams will draw from evidence-based practices subjected by Calculator to a series of social validation procedures in order to ensure their suitability for children with Angelman syndrome. These same practices and corresponding assessment protocols used in the study are expected to be applicable to a broader range of students with severe disabilities, not just those with AS.

"The general assumption is that inclusion is always better," says Calculator. "This has huge implications in terms of teacher training, service delivery and models for providing technical assistance. This study hopefully is going to move us closer toward identifying and, more importantly, implementing 'industrywide' standards to validate the quality of instructional programs and associated outcomes."