Studies show tool can identify individual needs, supports to help youths with autism, intellectual disabilities

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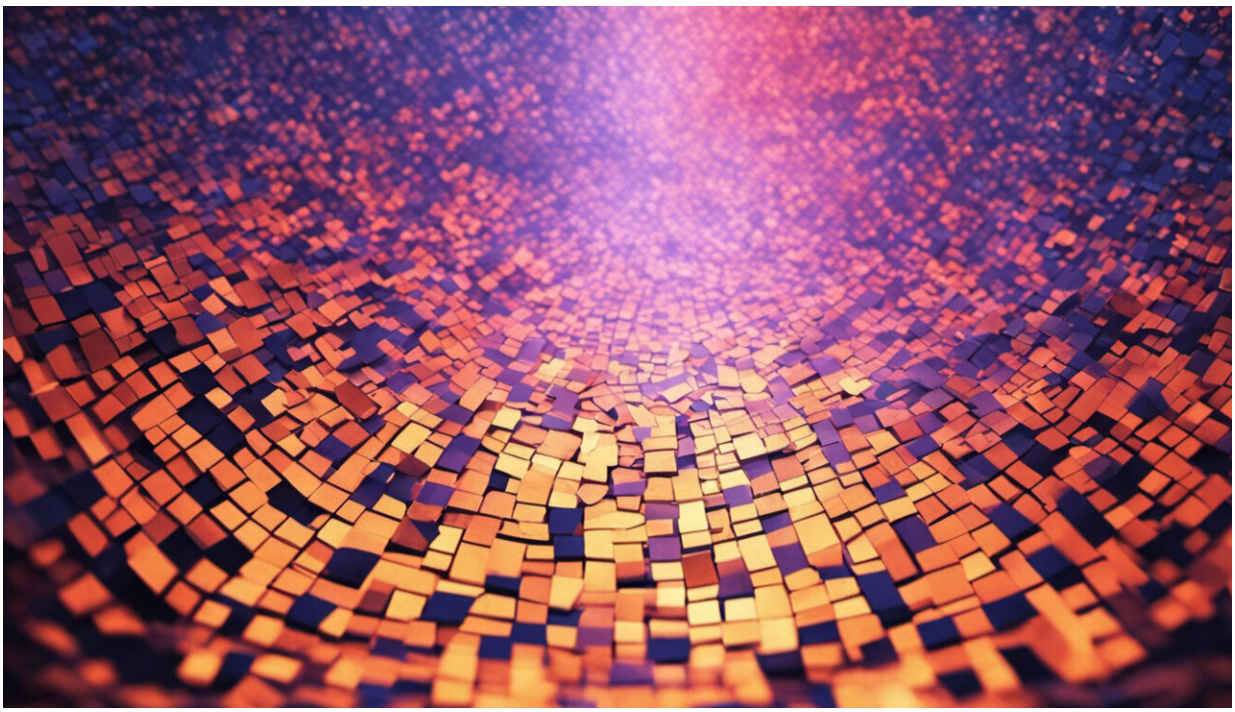

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To better serve families, University of Kansas researchers are examining the use of standardized assessments of support needs for children with autism spectrum disorders and intellectual disabilities. Two recently published studies demonstrated that the Supports Intensity Scale-

Children's version— a standardized, norm-referenced measure of support needs originally developed for children with intellectual disabilities—is a valid and reliable tool for children who also have autism spectrum disorders.

KU researchers led the development of the Supports Intensity Scale-Children's (SIS-C) version, which was published by the American Association on Intellectual and Developmental Disabilities in 2016. The SIS-C was developed to provide a children's version of the widely adopted Supports Intensity Scale-Adult (SIS-A). Until now, it was not known if the SIS-C was reliable in determining the support needs of children with autism spectrum disorders and intellectual disabilities and if the tool could identify support needs that may differ in youths with autism spectrum disorders, such as social activities. The researchers found that the SIS-C could identify those unique needs, opening the door for more effective supports planning.

Karrie Shogren, Michael Wehmeyer and James Thompson, University of Kansas researchers in the nationally No. 1-ranked public special education department and the Schiefelbusch Institute for Life Span Studies, are leading the work. The studies were published in the *Journal of Autism and Developmental Disorders* and Focus on Autism and Other Developmental Disabilities. The studies were co-authored by researchers at Texas Tech University, Ohio State University, Hastings College and Queens College.

"The SIS-C is innovative because before it was developed, there was not a standardized measure of support needs for children with disabilities. This research extends the application of the SIS-C, showing that we can use it with children with autism spectrum disorders to determine their needed supports for success in community environments," said Shogren, professor of special education and director of the Kansas University Center on Developmental Disabilities within the Schiefelbusch Institute.

"In understanding these needs we can plan for effective supports. Without such assessment information, educators, family members and other practitioners are often guessing at specific areas of support need, which is not always effective.

"This opens up doors for meaningful education planning for children with autism spectrum disorders that focuses on what children need to be successful, considering the unique needs that they have across life domains, including social activities," she said.

There is a common saying: "If you've met one child with autism, you've met one child with autism." Each individual's needs and abilities can vary widely from their peers, so having an assessment that can identify individual support needs enables educational supports to be tailored to an identified need, rather than a suspected need. And the SIS-C measures children's support needs across seven domains, including home, community and neighborhood, school participation, school learning, health and safety, social and advocacy activities.

"When there is a poor 'fit' between children's competencies and the demands of the environments where children live and learn, a need for support is created. What defines children with disabilities is their need for extraordinary supports, above and beyond the general population, to successfully participate in typical environments," Thompson, professor of special education, said. "Educators that use the SIS-C can better understand the types of settings and activities where students experience a poor fit, and they can identify and arrange supports that enable students to successfully participate."

SIS-C and the original SIS-A are available and in use in several states and have been translated into several languages as well. Knowing it is a valid way to identify and plan for supports for children with autism spectrum disorders and intellectual disabilities will help reach even more

with responses, strategies and interventions that support the children's growth.

"The SIS-C can help move the field toward individualized supports based on a valid understanding of the needs that each child has. In doing so, we can focus on the goals and vision that a child and their family have for the future," Shogren said. "But until now, there really haven't been reliable and valid assessments that pinpoint specific areas of needs to enable individualization of supports."

The SIS-C is administered after a child's diagnosis. A person trained in the scale conducts interviews with at least two people who know the child well, such as a family member and teacher. Questions are designed to understand support needs in the aforementioned seven domains. The approach shifts away from the focus on a child's deficiencies to understand what a student needs to be successful.

"As disability service systems increasingly adopt a supports paradigm, it is critical to have a valid and reliable measure for use with people with autism spectrum disorder. Supports-based services focus less on impairment and deficit and more on determining what supports do people need to be successful in typical environments," said Wehmeyer, chair of the Department of Education, Ross and Marianna Beach Distinguished Professor in Special Education and director of the Beach Center on Disability. "These studies are a first step. We certainly need to know more about how the support needs of people with ASD might differ from other groups so as to provide truly personalized supports to enable people to be successful."

Shogren, Thompson, Wehmeyer and colleagues previously published a book describing a framework for using the results of a SIS-A assessment to develop individualized supports plans with adults with disabilities. The researchers plan to continue to study how the SIS-C works for children

with autism spectrum disorders, including how it can be applied in school and community contexts to enable effective supports. This ongoing work can help build on a scale that provides educators and families more tools to improve young people's education, communication and social skills and ultimately a better quality of life. Thus far, one of the main values of the Supports Intensity Scale is that it is general enough to use be used widely, yet also able to be individualized and clearly detect the differences in individuals and their needs for support.

"Supports are a means to an end. Individualized supports will lead to greater participation and engagement in settings and activities, which will lead to greater learning and a more positive school experience for students, educators and families," Thompson said. "A focus on supports steers the conversation away from what students can't do because of their disabilities to what they can do when the right supports are in place."

Provided by University of Kansas

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