

Youth with autism spectrum disorder need better health care transition services

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As of 2014, approximately one out of every 68 children born has an autism spectrum disorder, according to the Centers for Disease Control and Prevention. Historically, less than one in four youth with ASD successfully transitions into a fully independent adult. Now, MU researcher Nancy Cheak-Zamora has received a \$500,000 Autism Research Program Idea Development Award to continue her research on ways in which health care programs can help youth with ASD become independent adults.

"The majority of individuals with ASD currently are 18 years old or younger, which means an influx of adults with ASD will enter the [health care](#) system throughout the next decade," said Cheak-Zamora, an assistant professor in the MU School of Health Professions and a researcher at the MU Thompson Center for Autism and Neurodevelopmental Disorders. "The U.S. health care system currently is unprepared to treat the needs of these adults. Previous research revealed that less than 25 percent of young adults with ASD secure employment, live independently, and possess adequate social networks. Young adults with ASD are less likely to gain the necessary skills to increase their independence, such as how to manage their [personal health care](#)."

ASD occurs on a spectrum and is characterized by impairments in verbal and nonverbal communication and social interactions, as well as restrictive or repetitive behaviors. A recent study published in JAMA Pediatrics reports the national cost of autism care in the U.S. alone is

more than \$236 billion each year.

"This study is designed to change the current standard in which providers and caregivers are the decision makers for [youth](#) with ASD," Cheak-Zamora said. "Our research will promote the idea that youth with autism deserve to be treated as adults and that they should experience an adult model of care whenever possible."

Cheak-Zamora's study will investigate how to help youth with autism increase their independence and make the transition to adulthood smoother. By developing resources for youth, families and health care providers, health care transition services are intended to assist young people in managing their health and self-care needs as they transition into adulthood.

Cheak-Zamora's project, "Improving Healthcare Transition Planning and Health-Related Independence for Youth with ASD and Their Families," will use focus groups and individual interviews to explore how caregivers and youth with autism define successful transitions into appropriate independence and what factors contribute to successful transitions. The researchers will use insights gained from these conversations to develop an ASD-specific measure to assess the level of independence and independence needs for [young adults](#) with autism. The measure then will be implemented at five autism clinics throughout the nation to determine its effectiveness in predicting transition success and independence.

"This project will provide youth with ASD and their families a voice to express their experiences and needs, and promote independent health and living skills for youth with ASD," Cheak-Zamora said.

Cheak-Zamora will conduct her research in conjunction with the MU Thompson Center for Autism and Neurodevelopmental Disorders. Other MU researchers who will work with Cheak-Zamora include David

Beversdorf, Janet Farmer and Michelle Teti.

The purpose of the Autism Research Program Idea Development Award is to fund research that improves the lives of individuals with ASD by promoting innovative research to advance the understanding of ASD and lead to improved outcomes. The U.S. Department of Defense funds the award as part of its Congressionally Directed Medical Research Programs that seek to fund innovative, high-impact research focused on diseases and disorders that affect the general public and members of the military and their families.

The MU Thompson Center is a national leader in confronting the challenges of [autism](#) and other developmental conditions through its collaborative research, training and service programs. Based on the medical home model, MU Thompson Center diagnostic, assessment and treatment services emphasize family-centered care that is comprehensive, coordinated, compassionate, culturally sensitive, and accessible. The center aims to support families from the point of initial contact through access to needed services in the community with routine follow-up care over time to ensure the best possible outcome for each child and family.

Provided by University of Missouri-Columbia

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