

NEWS

# Latino families face barriers on path to autism diagnosis

BY HANNAH FURFARO

22 JUNE 2017

Serious obstacles impede Latino families' quest for autism diagnosis and treatment in the United States. Challenges include a lack of information about autism and a concern that consulting experts might bring them legal trouble<sup>1</sup>.

The findings may help explain why Latino children with autism are diagnosed later on average than non-Latino white children in the U.S.<sup>2,3</sup>.

"It's pretty obvious now from national data that's been collected for about 10 years that these disparities exist. It's not a fluke, and they're not going away," says lead researcher **Katharine Zuckerman**, associate professor of general pediatrics at Oregon Health & Science University in Portland.

Zuckerman and her colleagues surveyed 352 parents of children with autism — 46 percent white and 54 percent Latino — in Portland, Denver and Los Angeles about their experiences getting an autism diagnosis for their child. All of the families had visited clinics in the **Autism Treatment Network**, an association of clinical sites supported by the nonprofit advocacy group Autism Speaks.

The survey revealed 19 barriers to care, 4 of which are specific to Latino families. The most common — reported by three-quarters of parents in the study — was the stress of the diagnostic process. Others include a lack of knowledge about autism and trouble navigating the medical system. On average, individual parents said they had run up against half of the barriers identified.

The next step is to find ways for families to overcome these barriers, says **Sandra Magaña**, professor of disability and human development at University of Illinois at Chicago, who was not involved in the study. "The field needs to really recognize there are a number of underserved communities, Latinos being one of them," she says. "We can't just ignore these populations."

## Immigrant issues:

Several hurdles are more prevalent among Latino parents than white ones, particularly among Latinos who speak little or no English. These parents had almost four times the odds of reporting a limited knowledge about autism as white parents.

About 16 percent of these parents said they were afraid to seek medical help because of legal issues — which could include fear of revealing their immigration status, Zuckerman says. The legal concerns are a more common concern than lack of access to an interpreter, which clinicians have long assumed to be a major barrier to care. The results appeared in the May issue of *Pediatrics*.

The study illustrates the importance of directly asking parents about the troubles they face, instead of simply ignoring or making assumptions about them, Zuckerman says.

“There’s a long legacy of research with minority communities that has been unfair to them,” Zuckerman says. “We really have a responsibility to do research that communities support and will also truly benefit from.”

Breaking down these barriers could help lower the average age of diagnosis, says Zuckerman. “The more we wait around, it’s just more kids who are not being identified until they’re really old, or not being identified at all,” she says.

A few research groups have made headway on this front. For example, **Bruno Anthony** and his colleagues at Georgetown University in Washington, D.C., have found that asking **Latino parents screening** questions orally instead of in writing helps flag more children for autism.

The next step, Anthony says, is to test treatments for autism that account for cultural differences.

### REFERENCES:

1. Zuckerman K.E. *et al. Pediatrics* **139**, e20163010 (2017) [PubMed](#)
2. Valicenti-McDermott M. *et al. J. Pediatr.* **161**, 554-556 (2012) [PubMed](#)
3. Magaña S. *et al. Intellect. Dev. Disabil.* **51**, 141-153 (2013) [PubMed](#)