

OPINION, Q&A

Filling autism knowledge gaps in Latin America: Q&A with Cecilia Montiel-Nava

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Few countries in Latin America or the Caribbean routinely collect even basic data on autism. So in 2016, **Cecilia Montiel-Nava**, director of the Behavior and Child Development Lab at the University of Texas Rio Grande Valley in Edinburg, Texas, teamed up with other researchers in the region to try to collect some of that information themselves.

Red Espectro Autista Latinoamerica (REAL) — in English, the Latin American Autism Spectrum Network — was born when Montiel-Nava, who is from Venezuela, and the other scientists shared the cost of hosting a website to solicit and gather survey data on autism prevalence, service access and caregiver needs.

Since then, Montiel-Nava and her collaborators have published 14 papers, including 7 in Spanish. Their most recent **results**, which appeared in January in *Autism*, detail trends on the age of autism diagnosis in Argentina, Brazil, Chile, the Dominican Republic, Uruguay and Venezuela. Montiel-Nava spoke with *Spectrum* about these findings, as well as the challenges of gathering data in places that lack an infrastructure for it.

This interview has been edited for length and clarity.

Spectrum: What obstacles have you and your colleagues faced in trying to collect data from these regions?

Cecilia Montiel-Nava: We don't have a sampling framework. We don't know how many people are out there, as the censuses in our countries are not that good. So we cannot make good estimates of how many people we need to sample to get data.

The other thing is funding. If you are going to collect data, you need to pay people to go and collect data. And the governments don't support research, not just in Latin American countries, but in

many low-resource countries. If you go to Asia, you're going to have these problems. If you go to Africa, they share these same challenges.

In Venezuela, there are food, medicine and electricity shortages, and we collected some information in 2016, which was when these problems kind of peaked. In the big picture, having a child with disabilities is not the top priority for families in Venezuela.

One of the other challenges is safety. I don't send my students to go and work in our neighborhoods because that's dangerous. In the past, we have worked around this by collecting data in schools, but that leaves out the children who do not go to school.

S: How do you try to surmount these obstacles?

CM-N: For this latest study, we used online surveys. But in our countries, internet penetrance is not that widespread, so we left out people without internet or a computer. That is something we need to be mindful about: If these numbers are true for this population that is more affluent, then what can we expect for those who have less?

S: How does looking at the average age of diagnosis fit into REAL's broader goals?

CM-N: Age of diagnosis is an indicator of outcomes. Early identification leads to children getting started with services, and the sooner they get the services, the better outcomes we can expect. But in Latin America, there is a scarcity of services and a lack of knowledge among professionals. Our work is part research, but part public health. As a network, we are also thinking about developing open-access resources for screening — not just translations, but adaptations.

We are thinking about the best ways to start improving access to diagnostic services, so we wanted to quantify and bring attention to that, to ask, "How is age of diagnosis in our countries?" and "What are the predictors?"

S: And what did you find?

CM-N: In general, parents were aware that something was different with their children at 22 months of age, but diagnosis came two years later. Parents really understood that they needed help, and the problem is not that parents are not aware, it's that the system isn't working right or is not paying attention to what parents are saying.

If a child is verbal, it takes longer to get a diagnosis because some professionals are not used to seeing children with strong language abilities diagnosed as autistic. If a child doesn't have cognitive impairment, they often don't get flagged until they are in the formal school system. And diagnosis takes longer for girls, because the system is not designed to identify autism in them.

S: These results are similar to trends reported in countries with more resources. What do you make of that?

CM-N: Because the people who participated were those who had internet, we are thinking that the people who answered our survey are people with more resources. And these were people living in cities, not rural areas, so we think that these results are actually underestimations.

When we try to publish our findings in a journal, the reviewers are sometimes unaware of all these challenges we have in collecting data. But for our countries, it's a huge breakthrough. So we are trying also to educate reviewers that there are different ways to do research. Maybe we are not complying with all the best methodology, but this is our first step. These are exploratory data. We are proud to be bringing awareness about what is happening in this region, what is happening in low-resource areas.

S: Were there any surprises in your results?

CM-N: We were surprised to see that depending on where you live, you're going to have a younger or older age of diagnosis. For example, living in Argentina was related to a lower age of diagnosis. As it happens, Argentina's legal framework is stronger than that of any other country in our network, and you cannot get services unless you get a diagnosis. That makes a difference. In other countries we surveyed — Venezuela and Uruguay, for example — they have laws, but they don't articulate how to implement them.

And if parents have private insurance, they tended to get an earlier diagnosis. All the countries in our sample have universal health coverage, so in theory, parents should get the services for free. In reality, the waiting lists are huge.

The last one is not surprising, but it is important: The presence of co-occurring medical conditions, such as seizures, will lead to earlier diagnosis because the child is going to be in the health system earlier, and it will be easier for them to get referrals to other providers.

S: You mentioned that internet access may play a role in the trends you identified. What other unmeasured variables could have influenced the data?

CM-N: We are just studying parent reports, so we don't have data on the actual diagnoses. Even though that is a bias, you are talking about a region without data. It is the first time that we are studying this, so maybe this is just the tip of the iceberg.

S: What are you doing to follow up on this work?

CM-N: We are working with the World Health Organization on a caregiver-skills training program, and there are some countries that have also implemented this. This information that we collect will

help us to go to the government and say, you know, “This is what is happening in your country.”

One of the members of the REAL network is interested in studying quality of life in adults with autism, so we have been talking about also developing and norming a screening for depression and suicidality in autistic adults.

We are also trying to work on early detection. One of my colleagues has been working on an early-identification program and a screening program in Mexico, and there is another going on in Peru. We are trying to offer the communities something back.

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