

COVID-19 added to the isolation among families facing autism

October 29 2020, by Jim Murez

Parenting can be hard enough, but parenting a child with autism while in quarantine during a deadly global pandemic adds an untold amount of stress to those families' already stressful lives.

Earlier this year, College of Education professor Laura Lee McIntyre was in the midst of a 16-week National Institutes of Health-funded study on families in Oregon and California with children who had autism. McIntyre's research focuses on providing supports for parents of young children with autism and other developmental disabilities.

Her study was using an intervention that she's been refining with an economically, racially and linguistically diverse sample, about half of whom were Spanish speakers, including some who spoke little or no English. The group met in person one evening a week as parents learned positive parenting strategies, stress-reduction techniques and other tools to help them and their children strengthen their relationships.

Then the pandemic struck. They halted face-to-face gatherings, but McIntyre and her counterpart in California resumed the classes via video chats. She also received permission from the NIH to add a component to her previous study, asking 77 families questions about how they were coping during the quarantine and the pandemic.

"What was interesting about our findings is we documented incredible stress and concern, particularly around the loss of services," said McIntyre, department head of special education and clinical sciences and

professor of school psychology. "These are families who already have challenges accessing services.

"And let's remember they're also experiencing racial injustice coupled with COVID," McIntyre said of the families. "I was concerned our attendance would take a nosedive, but families were motivated to continue because with other services being shut down and stopped, our services and our interventions continued. When doors were closing, we opened our virtual door and said yes, we wanted to continue to support you."

McIntyre found very little research on how families were coping with a pandemic while parenting a child with autism. She found none that had the ethnically, racially and linguistically diverse component that her study had.

Some families talked about lost employment or how the demands of their jobs increased because they were essential workers. Others talked about their fear of getting sick, and keeping their families safe and healthy.

"It was exponentially stressful for these families because it's not like they were just at home with a kid on vacation," McIntyre said. "All of the sudden they had to be their child's teacher, [speech therapist](#), behavioral therapist, occupational therapist—all services their child would normally get. Many parents didn't have a [high school diploma](#)."

Parents already had reported feelings of isolation prepandemic, and the sense they were being judged since autism isn't an obvious condition to bystanders.

"And for parents who feel like the best thing they can do is take their kid out to a playground and get out and socialize, that wasn't available

either," McIntyre said. "Understanding [social distancing](#) and [social norms](#) is hard for any 3-, 4- or 5-year-old. Add autism into the mix, add added activity level and impulsivity that is sometimes associated with autism and you have a recipe for disaster."

Amazingly, nearly all of the parents McIntyre and her team interviewed were able to find positive elements in this challenging environment.

"Almost every single one pointed to the added benefit of having more time with their child to understand more about where their child was developmentally and what supports their child needed to be successful," McIntyre said. "Some commented that they were able to work remotely with their child's teacher and understand more from a teacher's perspective how to better support their child."

McIntyre expects there to be [long-term effects](#) on these children, their siblings and their parents stemming from the pandemic's effect on limiting access to resources. She and her team plan to regularly re-interview the participants, starting this fall, as the pandemic has lasted longer than most expected.

"From parents' mental health perspective, there inevitably will be longer-term effects," McIntyre said. "There will also be longer-term effects on those kids with disabilities who are not getting the services they need during a critical time. In the world of early intervening, earlier is better. With missed opportunities early on, kindergarten, first-grade, second-grade teachers will not be equipped for the pandemic generations that are entering into elementary school, especially those kids with special needs that haven't been adequately addressed prior to entering kindergarten."

In addition to teachers, school psychologists, counselors, speech therapists and others in the education system who work with these

children will see soaring demand.

"That education system is going to be taxed in a way that we haven't seen before," McIntyre said.

McIntyre said the pandemic illustrates the benefits of investing in preventative measures and supports.

"That will help us weather storms like COVID or who knows what's next," she said. "The importance of prevention and prevention science as a discipline is that it really invests in bolstering families', communities' and schools' capacity to prevent problems before they become unmanageable."

Provided by University of Oregon

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