

NEWS

Autism researchers adapt studies for a socially distant world

BY LAURA DATTARO

30 APRIL 2020

When the coronavirus pandemic first forced universities and labs to close, **research teams raced** to save their work and adjust to a socially distant world. Now, weeks into the crisis, many scientists are moving their investigations to virtual and online formats, a shift that may bring lasting changes to autism research.

Some researchers are adapting existing studies to the new realities. Others are initiating entirely new projects that can be conducted remotely, including some related to the pandemic.

Antonio Hardan's team switched gears after closing a laboratory preschool that serves autistic children and suspending at-home therapy visits. Hardan, professor of psychiatry and behavioral sciences at Stanford University in California, seized the opportunity to launch a previously planned study. The study is intended to evaluate the **effectiveness of remotely training parents** to use a therapy called pivotal response treatment (PRT), which helps minimally verbal autistic children communicate¹.

The team had been running a small uncontrolled trial on remote PRT for the previous two years. In August, Hardan and his collaborator, **Grace Gengoux**, received institutional review board approval to conduct a larger, controlled trial.

"When we realized the only thing we were going to be able to offer families in terms of treatment during a shelter-in-place order was going to be a telehealth format, we decided that it was time to start recruiting," says Gengoux, clinical associate professor of psychiatry and behavioral sciences at Stanford.

They were able to enlist research assistants whose other projects are on hold, Hardan says.

The team aims to enroll 40 children: 20 in active treatment and 20 controls (who will be offered the

treatment at the end of the study). For 12 weeks, parents will receive PRT training with a therapist by video conference once or twice per week. Parents will then create 10-minute videos capturing how they applied the therapy in interactions with their children. They will submit the videos through Stanford's protected file-sharing program.

All aspects of the study can be done with a smartphone, Hardan says.

The researchers plan to use the videos to evaluate the children's language progress and the effectiveness of the parents' remote training. They also hope to learn if there is a subgroup of children who benefit more from the approach than others do, which could, even after the pandemic ends, help therapists determine who needs **access to in-person visits** and who does well with parent-facilitated treatment.

"In reality, these days we don't have enough therapists," Hardan says. "Training the parents is sometimes the best option we have."

Switching focus:

Other teams have also launched new studies as a result of the pandemic. A Swiss group had planned to test the effectiveness of a board game they had created to teach emotion-regulation skills to autistic children. With schools closed, the study is postponed until at least 2021.

The team instead put together a survey to assess how children with autism or various developmental conditions are **coping during the pandemic**. People with **Williams syndrome**, for example, can be highly social and may find shelter-in-place rules particularly difficult.

The researchers launched the English-language version of the survey on 8 April. They have since translated it into multiple languages, including French, German and Chinese, and they have collaborators in 14 countries so far. (Hardan is one of them.)

The group also plans to look at the effects of different countries' responses to the pandemic on children and families. Because the timing of the crisis varies among and within countries, the survey is designed to capture information about families' experiences over time.

In addition to providing valuable data, the study keeps the team active and engaged, says lead investigator **Andrea Samson**, professor of psychology at the University of Fribourg in Switzerland. "I think it's important to keep some sense of normality in all this, and focus on projects and have a sense that [the work] continues," she says.

Adapting a study:

Rather than designing a new study, some teams are working through the challenges of moving

ongoing projects entirely online.

In August, **Kevin Pelphrey**'s team at the University of Virginia in Charlottesville launched a long-term study of differences between boys and girls with autism, involving 1,500 children at seven research sites. They were preparing to begin a second wave of data collection when the pandemic hit.

Because interactions with study participants are protected by the U.S. Health Insurance Portability and Accountability Act, even calling families to cancel appointments presented a logistical challenge. Pelphrey did not want the research assistants making contact from their personal cell phones and computers, so his university ordered new work phones to be delivered to staff at home.

His team also devised ways to remotely conduct assessments that require children to look at images or videos. And they trained research assistants to talk participants through the consent process by phone or video chat.

The study includes survey questions about potentially dangerous behaviors, such as self-harm. Under normal circumstances, team members would arrange in-person visits if answers from parents indicated an urgent need for support. Now, they are instead reaching out by phone and following up with participants' doctors or law enforcement if the participants cannot immediately be reached.

"We have real clinical responsibility if certain answers come back," Pelphrey says. "We've got to be able to offer some help."

Permanent shift:

Moving studies to virtual formats raises serious questions about who is able to participate in autism research and access therapies, researchers say.

Some people will be more likely to participate remotely than in person because remote studies allow them to manage their own schedules and avoid traveling to distant research centers.

But for others, such as those without internet access, connecting to the research community will be even more difficult. This could exacerbate existing disparities in research participation.

"One of the many things that COVID-19 has shown us is how deep and consequential the digital and technological divide is in Australia and across the world," **Liz Pellicano**, professor of educational studies at Macquarie University in Sydney, Australia, wrote in an email. "Moving our research 'online' might well make our research more accessible to some autistic people, but it also might make it less accessible to those who are already from 'seldom heard' groups."

Still, many researchers expect that greater use of remote and virtual methods is here to stay, long after the coronavirus has receded. Though collection of some types of data, such as brain imaging, will always need a physical space, much of it will move online, informed by lessons learned during the pandemic.

“This experience, being sheltered at home and moving some therapies to being done remotely, is going to be transformative,” Hardan says. “We’re going to have more opportunities for remote treatment, and we have to start thinking about how to study that.”

REFERENCES:

1. Minjarez M.B. *et al. J. Autism Dev. Discord.* **41**, 92-101 (2011) [PubMed](#)