



INNOVATE

EVIDENCE-BASED MENTAL HEALTH RESEARCH

Impacts of COVID-19 on the Neurodevelopmental Community and a Plan for Continued Care

Access to early and sustained behavioral interventions is paramount to achieving optimal outcomes in individuals with neurodevelopmental disabilities, such as autism spectrum disorder, Down syndrome, and fragile X syndrome. These interventions are generally intensive and highly individualized, often delivered in person by trained clinicians either in the home, at a clinic, or at a community-based center.

Leonard Abbeduto, Ph.D., Professor of Psychiatry and Behavioral Sciences and Director of the MIND Institute, and Lauren Bullard, Ph.D., expect that many of these services are impacted by recent COVID-19-related closures. The use of telehealth likely mitigated some loss in service delivery. However, the rapid rollout of such programs raises concerns about variability and efficacy in services provided to families. Abbeduto and Bullard's research aims to shed light on the extent to which telehealth has been used, its acceptability to families and professionals, and its limitations.

The duo designed a project to document the impact of COVID-19 closures on clinical services and explore parental and professional views on the value, acceptability, and limits of telehealth-delivered services. Their goal is to inform telehealth-delivered interventions and services in the future. The study, titled "Impacts of COVID-19 on the Neurodevelopmental Community and a Plan for Continued Care," received one of two research pilot awards from the Center for Healthcare Policy and Research (CHPR), the Center for Health and Technology (CHT), and the Behavioral Health Center of Excellence (BHCOE) at UC Davis.

"I don't think technology is the answer to everything, but I think we've learned how fragile our system of service delivery is for people with disabilities," Abbeduto said. "My hope is that we can use this as an opportunity to develop a more robust evidence-based technology-augmented system to provide high quality care to families."

The research team will seek input from both providers and families through surveys, which will include questions about how their services were impacted due to COVID-19-related closures, the steps taken to mitigate these impacts, and how families are coping given the changes. In the event telehealth was used, the research team will assess the feasibility and challenges faced during the transition and identify barriers to conducting telehealth.

To determine the effect of the pandemic on families, the team will compare services received and family well-being at multiple time points to differentiate challenges experienced pre- and post-pandemic.

Families of youth with neurodevelopmental disorders often face barriers to receiving necessary early and sustained behavioral intervention services. These may include low availability of clinicians relative to demand, geographical distance between families and clinics and parents not having the time or resources



"We need to have alternative ways of providing help, not just in case there's another pandemic, but we need a more robust system of providing help and support to families all the way through the life course."

-Leonard Abbeduto, Ph.D.

to access intervention services. According to Abbeduto, barriers to care are detrimental to the developmental progress of many children with neurodevelopmental disorders and the existing challenges were only made worse by the COVID-19 pandemic.

"As a field, we have to be careful not to exacerbate inequities and disparities that already exist in care. If all we do is make care more convenient for the people who already have access, then we've done a disservice," Abbeduto said. "The potential lies in creating technology that is truly available to everyone."

It is important for the study to not only look at the challenges, but also the successes experienced during the current public health crisis, particularly the discovery of new ways of providing services that might be lower cost and serve more families. Abbeduto highlighted the effectiveness and convenience of using telehealth for certain therapies such as cognitive behavioral therapy for patients with anxiety. Additionally, he celebrated online communities that continue to provide training to providers who might otherwise not have had access.

"Providers discovered there's a lot more we can do with technology than we thought before. We started to think about having clinical programs that aren't so bounded

by the physical space," Abbeduto explained.

He expects that data collected in this project will shed light on the impact of COVID-19, including its associated closures and the necessary services provided to families of youth with neurodevelopmental disorders. The results will inform several external grant applications to fund a larger project aimed at bridging the gap in services provided to families, using a self-guided intervention platform and telehealth access to trained clinicians.

"We need to have alternative ways of providing help, not just in case there's another pandemic, but we need a more robust system of providing help and support to families all the way through the life course," Abbeduto said. "This project is really a roadmap for policy going forward but also for research that can fill in some gaps about how we can adapt technology to really help families."

1 Statham, H., Ponder, M., Richards, M., Hallowell, N., & Raymond, F. L. (2011). A family perspective of the value of a diagnosis for intellectual disability: experiences from a genetic research study. *British Journal of Learning Disabilities*, 39(1), 46-56.

2 Vismara, L. A., Young, G. S., & Rogers, S. J. (2012). Telehealth for expanding the reach of early autism training to parents. *Autism research and treatment*, 2012.

Behavioral Health Center of Excellence at UC Davis

UC Davis launched the Behavioral Health Center of Excellence in October 2014 to advance mental health research and policy with initial funding from the Mental Health Services Act. The Innovate series highlights the Center's research pilot award program.

behavioralhealth.ucdavis.edu
[@UCDbrainhealth](https://twitter.com/UCDbrainhealth)

UC DAVIS
BEHAVIORAL HEALTH CENTER
OF EXCELLENCE

Center for Healthcare Policy and Research

The Center of Healthcare Policy and Research was established in 1994 to conduct interdisciplinary and collaborative research and research synthesis to improve health outcomes and services, educate the next generation of health services researchers, and assist policymakers in formulating effective health policies. The funded pilot projects align with the mission of CHPR to improve healthcare outcomes and healthcare quality.

health.ucdavis.edu/chpr
[@UCD_CHPR](https://twitter.com/UCD_CHPR)

UC DAVIS
Center for Healthcare
Policy and Research