From the director

2020 has been a difficult year due to the COVID-19 pandemic and the pernicious effects of systemic racism. But the faculty, staff and trainees of the MIND Institute continue to meet our mission of helping individuals and families affected by the challenges of neurodevelopmental disabilities. These crises have brought us together and spurred innovation in our research, clinical care, training and outreach.

We’re using telehealth to continue research and provide clinical care when in-person visits are not an option for families, and we’ve developed procedures to make returning to the MIND Institute safe. Now, an increasing number of studies are seeing participants again and about half of patient visits in the Massie Family Clinic are on-site. MIND Institute researchers continue to publish important, peer-reviewed papers and secure new grants. You’ll see a few examples in this newsletter.

We have also evaluated our policies and priorities to ensure that we address barriers to equitable access to care and participation. This led us to create a Diversity, Equity, and Inclusion Committee to coordinate these efforts. In addition, we started a grant program to support trainee research focused on reducing the health and educational disparities experienced by historically marginalized individuals.

Philanthropy has fueled many of these efforts. Indeed, our community of supporters has “shown up” to help in so many ways during 2020. We continue to be humbled and motivated by your generosity.

Leonard Abbeduto
Director, UC Davis MIND Institute

MIND Summer Institute draws thousands from at least 15 countries

If you’re looking for a positive story amidst the disappointment of continual coronavirus cancellations, this is it.

Every year, the Center for Excellence in Developmental Disabilities at the MIND Institute offers the MIND Summer Institute on Neurodevelopmental Disabilities, a learning program that brings together experts, family members and caregivers. It’s typically an in-person event that attracts about 300 people.

This year, it reached thousands. The MIND Summer Institute, like so many other events, went virtual on August 7 to avoid any COVID-19 risk. More than 1,000 people registered for the Zoom event, and as many as 13,000 more have been reached through Facebook Live.

There was also another, unexpected benefit: attendees from all over the world. They logged on from Argentina, Brazil, Peru, the Philippines, Ecuador and more; at least 15 countries in all. The event was captioned live in Spanish and Korean.

“It was really the best possible outcome,” said Leonard Abbeduto, director of the
The National Institutes of Health has renewed the UC Davis MIND Institute’s Intellectual and Developmental Disabilities Research Center (IDDRC) with a five-year, $6.2 million grant.

“The NIH funding, combined with the generous support of the UC Davis School of Medicine and its Department of Psychiatry and Behavioral Sciences, allows us to create a strong and flexible infrastructure for our research,” said IDDRC Director Leonard Abbeduto, who also directs the MIND Institute. “It encourages innovation and facilitates interdisciplinary collaboration.”

The IDDRC acts like an engine for research at UC Davis Health and elsewhere by providing researchers with support and tools they likely wouldn’t be able to obtain otherwise.

“The funding allows us to provide expertise, technology and resources that an individual investigator couldn’t easily access or afford,” said Abbeduto.

Those resources are organized into five key areas, or scientific cores. The support includes everything from equipment, like highly specialized microscopes, to biostatistics experts who help analyze results, to scientists working in the center’s rodent behavior facilities. There’s also a large online registry that connects researchers with interested families.

The goal of the IDDRC is to bring disciplines together to increase the likelihood of finding treatments for neurodevelopmental disabilities such as autism, fragile X syndrome, or Down syndrome. “I think the potential for treatment has been really accelerated by us having the IDDRC,” said Abbeduto.

The center is one of only 14 in the country and was established in 2013.
Stuck at home? Check out this great new resource for families with young kids on the autism spectrum

“Help is in Your Hands” is an excellent new online resource for families with young children who have symptoms of or a diagnosis of autism spectrum disorder (ASD), as well as for early-intervention providers. The free website helpisinyourhands.org features 16 web-based video modules developed by the MIND Institute’s Sally Rogers and Aubyn Stahmer, both clinical psychologists, to help parents add simple intervention practices to their daily routines at home. It also offers several webinars for providers on coaching parents to support their children.

The modules are based on prominent research about how parents and parent coaches use the Early Start Denver Model (ESDM), an intervention to help kids with autism connect, communicate and learn through play. They are particularly helpful now, when COVID has led to the cancellation of many regular activities. “This resource will support families and early providers who don’t have access to training in evidence-based interventions,” Aubyn Stahmer said. “They can access them anytime and anywhere that works for them!”

“Help is in Your Hands” materials were originally built to support low-income families through a grant from the U.S. Department of Education.

MIND Institute provides care through telehealth

COVID-19 couldn’t stop MIND Institute providers from delivering much-needed care to their patients.

Fortuitously, they had already begun offering telehealth care services more than a year ago, mainly for patients who live far away or have transportation challenges. These providers — psychologists, social workers, pediatricians, psychiatrists and genetic specialists — can connect from their offices or clinic rooms. With the coronavirus pandemic, what was an option has become a necessity.

“Through telehealth, we are still available to support the children and families that we serve,” said Dorcas Liriano Roa, director of psychological and behavioral services for the Massie Family Clinic at the UC Davis MIND Institute. “The MIND psychologists, social workers and pediatricians have been very resourceful and learned about telehealth assessment practices in order to continue their work.”

Telehealth is also a tool for connecting families and children with neurodevelopmental disabilities. For example, the MIND Institute’s social skills training group for children with autism spectrum disorder and their families is now taking place via Zoom, with leaders implementing “game nights” for the participants and educational workshops for their parents.

“This was a creative way to maintain the group’s social cohesiveness when physical distancing is still critical,” Roa said.

“The was a creative way to maintain the group’s social cohesiveness when physical distancing is still critical.”

— Dorcas Liriano Roa, Director of Psychological and Behavioral Services, UC Davis MIND Institute
A MIND Institute study published in the *Journal of Neurodevelopmental Disorders* found more evidence for the efficacy of telehealth-delivered behavioral intervention in treating language problems in youth with fragile X syndrome (FXS). The authors, however, could not establish efficacy for the drug lovastatin as a treatment for learning or behavior problems in individuals with FXS, a single-gene disorder that is considered the leading inherited cause of intellectual disability.

Lovastatin is a widely used FDA-approved treatment for reducing cholesterol levels. It has been considered promising as a treatment for patients with FXS. The UC Davis investigators assessed whether the benefits of lovastatin combined with Parent-Implemented Language Intervention (PILI) would be greater than the benefits of PILI alone. The PILI model emphasizes a verbally responsive style of parental interaction to support the language development of children with FXS.

“This is one of the first published studies to combine behavioral and medication treatment in fragile X syndrome,” said Angela John Thurman, lead author and assistant researcher in the Department of Psychiatry and Behavioral Sciences and MIND Institute faculty member.

The study was a 20-week, randomized, double-blind controlled trial, with 30 participants between the ages of 10 and 17 with FXS. They were separated into two groups. One group took lovastatin and the other took a placebo. A researcher delivered PILI through video teleconferencing to the families of all participants for 12 weeks.

Both groups demonstrated significant improvements in language skills. The magnitude of change observed across the two groups was comparable, providing support for the efficacy of the use of PILI in youth with FXS. The medication, however, showed no evidence of efficacy.

“The study suggests that while we pursue medical treatments, we must also do more to develop behavioral and other nonmedical interventions.”

— Leonard Abbeduto, Director, UC Davis MIND Institute

“...while we pursue medical treatments, we must also do more to develop behavioral and other nonmedical interventions.”

— Leonard Abbeduto, Director, UC Davis MIND Institute
The MIND Institute boasts three of the top ten autism studies of 2019

Every year Autism Speaks selects the best autism research published in scientific journals, and for 2019, three of the top ten studies chosen were done by UC Davis MIND Institute researchers. The organization, which is the largest autism advocacy group in the U.S., selects studies that “advance its mission of enhancing lives today and accelerating a spectrum of solutions for tomorrow.”

The three studies selected by Autism Speaks came from the MIND Institute’s Collaborative START Lab. They were chosen out of more than 2,000 autism research reports.

“We are very proud of the research conducted by MIND Institute investigators,” said Leonard Abbeduto, director of the UC Davis MIND Institute. “It is advancing our understanding of autism and exploring ways to improve the quality of life for individuals and their families.”

The studies selected:

- The study published by Allison Nahmias, Aubyn Stahmer and their colleagues at the University of Pennsylvania in the *Journal of Child Psychology and Psychiatry*, which pointed to the large gaps in outcomes of early intervention programs for children with autism spectrum disorder. They found that early interventions associated with universities and hospitals tended to be superior to those provided in community settings.
- The research published in *Autism* by Aubyn Stahmer and Peter Mundy which highlighted the need to develop “systems of support” to help guide students with autism and their families through new school transitions. The study found that effective strategies during such stressful transitions included personalized support, parent information and improved communication.

The three studies selected by Autism Speaks came from the MIND Institute’s Collaborative START Lab. They were chosen out of more than 2,000 autism research reports.
The multi-university team of researchers found that ELS, a set of procedures for measuring language skills, yielded five language-related outcome measures that may be useful for treatment studies in intellectual disabilities, especially FXS. Outcome measures are used to detect meaningful change in the symptoms of a disease or disorder.

This is the first study to validate ELS procedures for studies of treatment efficacy in FXS or any intellectual disability condition. It included 106 participants between the ages of 6 and 23, with IQ levels within the range of intellectual disability (IQ < 70) and with FXS. The researchers collected samples of the participants’ speech during their natural interaction with the study examiners, as well as samples while participants narrated a story in a wordless picture book.

Based on the analysis of the conversation and narration language samples, the researchers derived five language outcome measures: talkativeness, lexical diversity (vocabulary), syntax, dysfluency (utterance planning), and unintelligibility (speech articulation).

The ELS measures were generally valid and reliable across the range of ages, IQs and autism symptom severity. They, however, are more challenging and have less adequate statistical properties for individuals with FXS and who are younger than 12 years.

“Most importantly, the measures are functional for the individual,” Abbeduto said. “If a treatment can improve language, it can have far reaching benefits for the individual at school, in the workplace, with peers and beyond.”

The researchers are sharing manuals with the research community for conversation and narration including procedures for administration, training and assessment of fidelity. The study was published in the Journal of Neurodevelopmental Disorders.

Andrea McDuffie from UC Davis was also a co-author.

Funding for the study came from the National Institutes of Health, grants R01HD074346, U54HD079125, and ULTR001860.
David Amaral elected to the National Academy of Medicine

David Amaral, distinguished professor and Beneto Foundation Chair in the Department of Psychiatry and Behavioral Sciences and the MIND Institute, has been elected to the prestigious National Academy of Medicine.

An autism expert, Amaral joins an elite group of physicians and scientists in the National Academy of Medicine. Only 100 new members are elected each year from the U.S. He is one of 13 UC Davis faculty members who have been elected to the Academy since its founding in 1970 and the only one from UC Davis elected in 2019.

Election to the National Academy of Medicine is considered one of the highest honors in the fields of health and medicine. The honor recognizes individuals who have demonstrated outstanding professional achievement and commitment to service. New members are elected by current members who have made major contributions to the advancement of the medical sciences, health care and public health.

David Amaral, Faculty Professor

Amaral, who spent the early part of his career at the Salk Institute for Biological Studies, joined UC Davis in 1995 as a professor in the Department of Psychiatry and Behavioral Sciences and the Center for Neuroscience. He was the founding research director of the MIND Institute. For the past 20 years his focus has been on understanding the biological bases of autism spectrum disorder. He coordinates a comprehensive and multidisciplinary analysis of children with autism called the Autism Phenome Project. He is also the director of Autism BrainNet, which uses postmortem brain tissue for autism research.

“I am very excited to become a member of this prestigious organization,” said Amaral. “I look forward to working with my colleagues in the National Academy of Medicine to increase research and education about autism and other neurodevelopmental disorders and to foster more enlightened treatment of people with autism and their caregivers.”

Amaral also directs the National Institutes of Health Autism Center of Excellence working to provide innovative and targeted autism treatments. He has held numerous national leadership positions in autism research organizations, edits a national autism journal, and published more than 300 papers. In 2016 he was appointed to the Interagency Autism Coordinating Committee by the Secretary of Health and Human Services.

Major new grant to study infants at higher risk for ADHD and ASD

Meghan Miller, assistant professor in the Department of Psychiatry and Behavioral Sciences and the MIND Institute, has been awarded a $3.65 million, five-year grant from the National Institutes of Mental Health to fund her “Learning about Autism and ADHD Markers in Babies” (LAAMB) study.

Meghan Miller, Faculty Professor

“We are thrilled that this grant will help support our work in investigating early signs of social communication and self-regulation difficulties among infants at risk,” Miller said. “Through this study, we hope to develop a better understanding of early indicators of ASD and ADHD.”

In the U.S., about 1 in 54 children has been identified with autism spectrum disorder (ASD) and approximately 5.8% of children are diagnosed with attention-deficit hyperactivity disorder (ADHD). Studies show that younger siblings of children with ASD or ADHD have higher risks for both disorders.

The LAAMB study will focus on infant siblings of typically developing children and on infants with at least one older sibling diagnosed with ADHD or ASD. Researchers will follow the development of the infants between 6 and 36 months of age and monitor their attention skills, emotion regulation, self-control, and social and communication skills.

“By learning more about the links between self-regulation and social communication problems during early development, we hope to help improve early detection of ASD and ADHD,” Miller said.

Findings from the study may also help inform the development of interventions for infants and toddlers at risk of ADHD or ASD.

“We are thrilled that this grant will help support our work in investigating early signs of social communication and self-regulation difficulties among infants at risk.” — Meghan Miller
New National Council of Visitors gains three new members

The MIND Institute National Council of Visitors has welcomed three new members; Marji Dunn, Shari Silver and Robyn Prime.

Marji Dunn

Marji first learned of the MIND Institute while serving on the former UC Davis Medical Center Leadership Council. She later brought her son, Patrick, to the MIND for an assessment after he had been diagnosed with attention deficit disorder. During that visit, with psychologist David Hessl, the Dunns learned that Patrick had dysgraphia, a learning disability. Hessl later visited Patrick’s school to provide education about the disability with school personnel and the district’s special education teachers.

Marji said she is looking forward to getting involved on the council and hopes to focus on community outreach. “I would like to be a support to parents,” she said. “When your child has a diagnosis, it’s scary, and you think you’re alone.”

Patrick is now 28 years old and doing well, Marji added, working as a drone pilot in Sacramento.

“I would like to be a support to parents. When your child has a diagnosis, it’s scary, and you think you’re alone.”

— Marji Dunn

Robyn Prime

Robyn is a resident of Chico, California, and has a long history with the MIND Institute. “The MIND Institute has provided medical care since 2006 for our son who is now 45 years old. As a result, his and our family’s quality of life has been improved enormously,” she said.

“As a resident of Chico, our community and our family are forever grateful for the caring staff at the MIND.”

— Robyn Prime

Prime said she appreciates the fact that MIND Institute staff members have participated in the Autism Symposium at CSU Chico and provide guidance to their staff involved with the Autism clinic. “These are examples of the MIND’s commitment to reach out and educate. As a resident of Chico, our community and our family are forever grateful for the caring staff at the MIND.”
Shari Silver

Shari is a resident of Lynbrook, New York. When her son Justin was diagnosed in 2006 with fragile X syndrome, the one piece of advice she and her husband Brian heard consistently was “Get to the MIND Institute to see Dr. Randi Hagerman.” A year later, they had their first visit and left with a full evaluation with Dr. Hagerman and a better understanding of how to help him. “During that visit, we were so overwhelmed by the dedication and work being done in the area of fragile X,” she said.

The family has since established a nonprofit, Fly With Me Fund, so that families can travel to fragile X clinics like the clinic at the MIND, and is very involved with the National Fragile X Foundation.

“With initiatives leading to the development of effective treatments, telehealth innovations through the Big Idea Program and Dr. David Hessl’s iBehavior App, my husband and I proudly maintain a commitment to support the MIND Institute.”

— Shari Silver

“The MIND is truly what keeps me hopeful for Justin’s future and for the greater fragile X community,” Shari said. “With initiatives leading to the development of effective treatments, telehealth innovations through the Big Idea Program and Dr. David Hessl’s iBehavior App, my husband and I proudly maintain a commitment to support the MIND Institute.”

The National Council of Visitors is a group of nationally and internationally respected leaders who are enthusiastically committed to support the MIND Institute’s mission of advancing research into the causes of and treatments for neurodevelopmental disabilities, and to ensuring superior patient care to individuals diagnosed with these conditions.
Development Update

My name is Marcus Frost and I am just finishing up my first year as director of development for the MIND Institute. Working in support of families impacted by neurodevelopmental disabilities is something that my whole family is extremely passionate about. My wife, Moria Frost, is a board-certified behavior analyst who supervises treatment for children on the autism spectrum and other neurodevelopmental disabilities. I am super excited to be a part of the MIND’s incredible team of faculty, staff and volunteers. While I have been working as a professional fundraiser in higher education for the past 10+ years, I can say I have never worked at a place that leaves me as routinely inspired as the UC Davis MIND Institute.

Some specific MIND Institute initiatives I want to share are:

**Autism Community and Technology (ACT)**

ACT is focused on putting leading-edge technologies into the hands of community providers and families near and far, thereby empowering individuals and loved ones to manage their own care, in their own communities, regardless of economic status or location.

**Maternal gestational health**

Current research indicates that while genetic risk factors play a key role in autism spectrum disorder, environmental exposures during pregnancy and the early postnatal period have an important influence on child neurodevelopmental outcome. The MIND Institute has an impressive group of young and established scientists working to identify these environmental risk factors, and to find the keys to maternal gestational health with respect to neurodevelopmental disabilities.

**Interventional genetics**

Advancing molecular therapies to improve quality of life for patients and their families with rare genetic disorder diagnoses requires a multidisciplinary team of clinicians, bench and translational scientists, regulatory and process specialists, parent advocates and industry partners. It literally takes a village. This is the environment we have established at the Center for Interventional Genetics at the UC Davis MIND Institute. The interventional genetics team at the MIND Institute is one-of-a-kind in that we are trying to work from many angles including patients, family members, patient-derived cells, neuronal cell models with fluorescent labels and in vivo (live, awake behaving) model systems to focus and reverse the molecular cause of the disorder and its devastating impact. Recent advances in gene editing and targeted gene regulation have now made it possible to attack the root cause of the problem, not just the symptoms and develop “curative” therapies over dampening of one symptom or the other with side effects.

**The transition to adulthood**

For children with neurodevelopmental disabilities, graduating from high school is often referred to as “Falling Off the Cliff.” This is due to the increase in anxiety for both parents and students regarding the lack of future resources. Those resources end abruptly, and families are forced to figure out how to navigate society with limited support. The MIND Institute is committed to researching and influencing programs and policies for housing, employment, post-secondary education, and more as youth with neurodevelopmental disabilities transition to adulthood.

“Thanks for being such a welcoming group. I hope to have the opportunity to meet with each of you.”

— Marcus Frost, Director of Development, MIND Institute
The MIND Institute offers a variety of events throughout the year, including fun activities for the whole family, lectures from experts on the latest research, and a variety of support groups. To learn more, please visit health.ucdavis.edu/mindinstitute/events and click on news and events.

Virtual Talent Showcase spotlights, connects MIND Institute kids and families

It may have been a virtual event, but the connections made during the UC Davis MIND Institute Talent Showcase were as real as it gets.

For about 45 minutes on an evening in early October, more than 50 patients, family members, supporters, faculty members and staff logged on to Zoom to celebrate the talents of our community. There were nine pre-recorded acts, representing a wide range of ages and skills, including pianists, artists, stop-motion moviemakers, a singer, a video game expert and a hands-free bicyclist.

“I was thrilled with the turnout,” said Erin Roseborough, child life specialist at the MIND Institute and an organizer of the event.

In between acts, the Zoom chat box was buzzing with excited chatter, including these supportive comments:

“So beautiful! An amazing story with beautiful animation!”

“Beautiful piano playing!”

“I can relate to the feelings on your video.”

“Your voice acting was AMAZING!”

“You are so fearless, I love it!”

“This song makes my heart melt. Great job!”

“My favorite part was reading the comments the participants were sending to each other in the chat and seeing their expressions when they watched their own performances or those of the other participants,” Roseborough said.

For the past two years, the MIND Institute held a live, in-person talent show, but organizers adapted the gathering due to COVID-19.

“We understand how hard this year has been for families,” said Veronica Tuss, child life specialist at the MIND Institute and an organizer of the showcase. “Our MIND Institute families face a heightened challenge as so many of the children we serve have concrete routines and comforts that have been severely disrupted during the pandemic. We want them to know that we recognize their resiliency and that we will work just as hard to continue to support them regardless of what the circumstances may bring,” she said.

The virtual Talent Showcase is one of many Family Time at the MIND events, which are open to the public and are designed to build community.
The fourth annual Give Day smashes previous records

Give Day 2020 was an action-packed online fundraising drive to support UC Davis students, faculty, and university programs. On April 17 and 18, 2020, the MIND Institute had its most successful Give Day ever, more than doubling the previous record for dollars raised. The MIND received 93 gifts totaling $43,830! This includes meeting the Challenge grant of $20,000 which will go to support the MIND Institute’s transition to adulthood programs. Your support of the MIND Institute impacts the lives of countless families and is very much appreciated. Thank you!

MIND Summer Institute continued from front page

MIND Institute, “The opportunity to have attendees from all over the world learning and contributing benefitted everyone.”

The event focused on the research and experiences of girls and women with autism. It featured presentations by the MIND Institute’s Christine Wu Nordahl on camouflage — something women with autism report doing more often — and the MIND Institute’s Meghan Miller, who focused on the intersection of autism and attention deficit hyperactivity disorder.

The MIND Summer Institute also featured a panel of courageous women who shared their own experiences with autism. They included Kristen Godfrey, a UC Davis Health employee, Erica Mineo, a UC Davis pre-veterinary student and two UC Davis graduates — Chloe Rankin, a motivational speaker on autism and Lisa Malins, a bioinformatician.

Malins had some inspirational advice: “I want you to be your best autistic self. Just be you. You don’t have to change who you are for anyone, because your best version of yourself will always be better than your best version of someone else,” she said.

You can watch the full recorded event on the MIND Institute’s YouTube page.